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ABSTRACT

Since 1994, the American Indian Rehabilitation Research and Training Center has been sharing successful research strategies related to disabilities and rehabilitation with indigenous people in Oaxaca, Mexico. Its first two projects identified the needs of indigenous people with disabilities in three geographic regions of Oaxaca and worked with a grassroots organization to create solidarity among people with disabilities in the Mixteca region, Oaxaca. This report describes the Center's third project, which assessed the feasibility of conducting major research and training projects involving indigenous people with disabilities in a remote, rural community: Totontepec Villa de Morelos, Mixe, Oaxaca. An introduction describes the Indian nations of Mexico; history of the Mixe people; characteristics of the Mixe language; political, geographic, and economic aspects of Mixe District; and Mixe concepts related to health, illness, and traditional treatments for persons with disabilities. A survey of 64 Mixe people with disabilities and ethnographic interviews with 12 disabled adults and family members identified the most common disabilities and needs among men, women, and children; disability definitions; available services; effects on quality of life; educational and employment needs; family assistance; needs of family members; concerns for the future; attitudes about responsibility to help; and recommendations. Appendices include descriptions of the Mixe and of the First Congress Regarding Disability in the Mixteca (Juan Areli Bernal Alcantara), the survey instrument (in Spanish and Mixe), interview questions, and other project documents. (Contains 25 references.) (SV)

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Vecinos y Rehabilitation (Phase III): Assessing the Needs and Resources of Indigenous People with Disabilities in the Sierra Mixe

Final Report

1998

Principal Investigator: Catherine A. Marshall, Ph.D., CRC

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Acknowledgments

Successful research cannot take place without the support and involvement of key individuals in local communities. Many people working together contributed to making this research project a success. The authors would like to acknowledge the considerable work that the volunteer interviewers put into this project. These were the people who went throughout the town of Totontepec to interview indigenous people with disabilities. The interviewers were Raquel Rivera Gomez, Elda Bernal Alcántara, Juan Arelí Bernal Alcántara, and Adrián Rojas Martínez. Thanks go to Ovaldo Galicia García, President of the Association of People with Disabilities in the Mixteca, who gave us valuable support and advice based on his experiences as the local research coordinator for the *Vecinos Project, Phase II.* We would like to acknowledge the time and valuable contributions made to this research effort by Ela Yazzie-King during her presence at the community meeting in Totontepec Villa de Morelos where we discussed the research results with the Mixe community. In addition, we would like to acknowledge her insightful recommendations (included in this report) for the continuation of the *Vecinos Project,* as well as the exchange of information and experience among indigenous peoples with disabilities. We are very much indebted to persons of the Project Advisory Committee who contributed their time, energy, resources, and support to the project. Finally, we would like to acknowledge the individuals who we view as the Project Support Group--individuals who, from time to time, have told us that they value the work we are doing and support our belief that Mexico and the United States should be working together to benefit indigenous people with disabilities.

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Summary

Researchers from the American Indian Rehabilitation Research and Training Center (AIRRTC) have spent nearly 15 years documenting the needs of American Indians with disabilities on a nationwide basis. Due to a supplemental grant which was first awarded to the AIRRTC from the National Institute on Disability and Rehabilitation Research (NIDRR) in September, 1994, researchers had the opportunity to share successful AIRRTC research strategies with indigenous people in Oaxaca, Mexico. The initial project led to the identification of the needs of indigenous people with disabilities in three geographic areas in the state of Oaxaca, Mexico (the *Capital*, the *Mountains*, and the *Coast*).

The subsequent project, entitled "Vecinos y Rehabilitation (Phase II): Assessing the Needs and Resources of Indigenous People with Disabilities in the Mixteca Region of Oaxaca, Mexico," was also funded by a supplemental grant awarded to the AIRRTC from NIDRR. To accomplish the objectives of this research effort, researchers from the AIRRTC worked very closely with a grassroots, non-profit organization, the *Associación de Discapacitados de la Mixteca* (Association of People with Disabilities from the Mixteca), the mission of which is to create solidarity among people with disabilities in the Mixteca region.

NIDRR awarded the AIRRTC a third supplemental grant to fund the project "Vecinos y Rehabilitation (Phase III): Assessing the Needs and Resources of Indigenous People in the Sierra Mixe." The purpose of this project was to:

1. Establish the feasibility of conducting major research and training projects involving indigenous people with disabilities in a **remote,**

rural community, that is, Totontepec Villa de Morelos, Mixe (pronounced *Me-hay*), Oaxaca, Mexico.

2. To continue to develop a program of information exchange between Mexico and the United States involving experts in the field of rehabilitation and Native peoples.

The Director of the Mixe Cultural Institute in Totontepec, Mr. Juan Arelí Bernal Alcántara, agreed to serve as the on-site research coordinator. Under Mr. Bernal Alcántara's direction, a total of 64 surveys were completed. In addition, six adults with disabilities and six family members of people with disabilities participated in ethnographic interviews. All of the respondents reported that their ethnicity was Mixe. The majority of the respondents said that their first language was Mixe. In terms of gender, the majority of the respondents were female. The majority of the respondents were also adults. The data demonstrated that among all respondents poor vision, arthritis, "muscular dystrophy" (any type of muscle weakness; any type of muscular degeneration), blindness, and deafness were the most common disabilities. The quantitative results indicated that the greatest needs among the 64 respondents with disabilities were medical attention, family support, physical rehabilitation, and health. The qualitative results indicated that proper medical attention, physical rehabilitation, and health were very difficult to obtain unless a person with a disability had access to money.

The results of this survey were presented to people with disabilities and their families, social and health care workers, and city and state government officials at a community meeting held in Totontepec, September 28 and 29, 1997. Ms. Ela Yazzie-King, a Navajo woman with a disability and disability advocate, traveled to Totontepec to present at the meeting.

Recommendations included the need to continue to develop education opportunities for people with disabilities in Totontepec, children in particular; to seek employment opportunities for people with disabilities in Totontepec; to create a support group for people with disabilities and their family members, where they can talk about their needs and problems and work together to find solutions; and, aggressively seek opportunities to bring specialized medical doctors to Totontepec at least once a month to serve those people who need specialized medical attention. After visiting Totontepec, Ms. Yazzie-King recommended that the types of assistive technology indigenous people in rural areas have developed (devices as simple as using a rubber band to hold a spoon) be documented and shared with other persons who have disabilities but minimal fiscal resources. In addition, Ms. Yazzie-King recommended that the plants and herbs that the Mixe use to alleviate health-related problems associated with disabilities (such as in the case of spinal cord injuries, the prevention of kidney problems is believed to be achieved through use of the plant *Guia de chayote* [Sechium edule L.]) be studied and shared with other people with disabilities. Finally, Ms. Yazzie-King recommended that both respite and paraprofessional in-home outreach programs be developed in Totontepec in order to provide support to the family members of persons with disabilities, as well as offer personal assistance to persons with disabilities.

Vecinos y Rehabilitation (Phase III): Assessing the Needs and Resources of Indigenous People with Disabilities in the Sierra Mixe

The Rehabilitation Act of 1973, as amended in 1992, states that National Institute on Disability and Rehabilitation Research (NIDRR) funds may be used to "conduct . . . a program for international rehabilitation research, demonstration, and training . . . , and initiating a program to exchange experts and technical assistance in the field of rehabilitation personnel." We believe that access to health care/human services, as well as the needs of indigenous people with disabilities, are areas in which Mexico and the United States can work more closely together. According to Dr. Paul Leung, rehabilitation counselor educator and advocate of cross-cultural understanding: "I have suggested from time to time that we must share ourselves and that we must do so on a global level" (1996, p. 4). This observation makes even more sense when one considers the comments of President Clinton's senior White House counselor, Thomas McLarty, when he noted that "Mexico [is] a neighbor, where we share an 1,800-mile border; a major partner, our third-largest trading partner, with over $130 billion of trade between the two countries--that's substantial, 800,000 American jobs directly related to exports from Mexico--and a friend" ("Clinton's goal," 1997, 12A). In response to the question, "Why should a reader in Chicago or Seattle care about U.S.-Mexico relations?," McLarty added,

> We are inexorably linked in terms of our economic futures with our third-largest trading partner, and that directly affects people's lives on

> Main Street. . . . Our exports are growing at about twice the rate to Latin America [as] they are with other parts of the world. By the year 2010, our exports to Latin America will be greater than the European Union and Japan combined (p. 12A).

Similarly, according to political scientist Jorge Castañeda (1995), after approval of the North American Free Trade Agreement (NAFTA) and the 1995 economic collapse of Mexico, "Mexico had suddenly become terribly important for the U.S. **Unlike so many other countries in the post-Cold War world, what occurred in Mexico actually affected Americans in all walks of life, whatever their awareness of this relationship may have been"** (p. 1, emphasis added). Specifically, Castañeda concluded that "Mexico's economic implications for the United States involve, to one degree or another, all Americans" (p. 13). However, it appears to be true that most Americans know little of Mexico other than its beaches, and less about its indigenous peoples. Again, according to Castañeda (1995), at least the Chiapas uprising in 1994 "highlighted the enduring marginalization, poverty, and discrimination suffered by the hemisphere's indigenous communities . . . and emphasized the reformist nature of their struggle and demands: land for the peasants, dignity for Indians, democracy and free elections for all Mexicans" (pp. 84-85).

Summary of Accomplishments of the Vecinos Project: Phase I and Phase II

On September 26, 1994, the American Indian Rehabilitation Research and Training Center (AIRRTC) at Northern Arizona University was awarded its first supplemental grant to conduct research in the state of Oaxaca, Mexico. A year later, with the successful completion of this research project, the

AIRRTC was awarded a second grant to conduct research in rural areas in the Mixteca region of Oaxaca. The purpose of both of these projects was to:

1. Establish the feasibility of conducting major research and training projects involving indigenous people with disabilities in Mexico.
2. To initiate a program of information exchange in Mexico involving experts in the field of rehabilitation and Native peoples.

To accomplish the objectives of this research, project researchers from the AIRRTC worked very closely with two consumer-initiated, consumer-driven organizations in Oaxaca, *Acceso Libre* [Free Access] and *Asociación de Discapacitados de la Mixteca* (ADM) [Association of People with Disabilities from the Mixteca].

Research and training at the AIRRTC are organized around four program Core Areas. Core Area I is aimed at identifying and facilitating effective and culturally appropriate rehabilitation services for American Indians with disabilities. Two NIDRR priorities addressed by Core Area I research and training activities are: (1) Develop, demonstrate, and evaluate culturally-relevant vocational rehabilitation techniques for use in the development of effective services to American Indians; (2) Develop models to improve rehabilitation and independent living services for American Indians with disabilities. The research projects, *Vecinos y Rehabilitation* (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996), *Vecinos y Rehabilitation: Phase II* (Marshall, Gotto, & Galicia García, 1998), and the present project, *Vecinos y Rehabilitation: Phase III*, allow AIRRTC researchers to address these priorities. In working directly with staff, for example, from *Acceso Libre* and ADM, researchers are obtaining direct input regarding the culturally-relevant services needed by indigenous populations in Oaxaca--services which can also apply to the needs of American Indians. All phases of

Vecinos y Rehabilitation have been conducted utilizing the philosophy and methods associated with participatory action research (Bruyère, 1993).

Vecinos y Rehabilitation: Phase I

The two co-coordinators of *Acceso Libre,* Germán Pérez Cruz and Pedro Flores Rey, served as the on-site research coordinators for the project and were based in Oaxaca City (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996). Both Mr. Pérez and Mr. Flores were of Zapotec heritage and had long been grassroots, consumer leaders of people with disabilities. Their knowledge of the indigenous cultures of Oaxaca was essential to the success of this project, particularly as regards the development of culturally-sensitive research instrumentation and procedures, as well as the culturally-appropriate interpretation of the data.

Early in the project, the principal investigator (PI), Dr. Catherine Marshall, and the on-site research coordinators met with key government officials and decision makers, health care educators, community service representatives, and indigenous people with disabilities in order to identify a Project Advisory Committee (PAC). The role of the PAC was to help in the process of developing specific procedures for collecting data. For example, in these initial meetings, suggestions were made regarding how participants for the project could be contacted, as well as suggestions for the survey instrument that was to be developed. The final survey instrument included questions regarding education level, type of disability, employment status, and the needs of the participants. Both quantitative and qualitative data were collected from 232 individuals by people with disabilities who either worked for, or volunteered with, *Acceso Libre.*

Vecinos y Rehabilitation: Phase II

The Mixteca region in the western part of the state of Oaxaca, was selected as the target site for the second phase of the *Vecinos y Rehabilitation* project (Marshall, Gotto, & Galicia García, 1998) due to the large number of indigenous people who lived in its rural communities (Chance, 1989; Cook & Borah, 1968). The city of Huajuapan de León served as the base for the project for two reasons:

1. It is centrally located within the Mixteca region.
2. The PI had established contacts in the area.

A linkage to the Mixteca region was initially made through contacts of the first phase of *Vecinos y Rehabilitation* (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996). The PI first visited Huajuapan de León in October, 1995. It was on this trip that Dr. Marshall initially met Mr. Ovaldo Galicia García, President of ADM. Mr. Galicia García subsequently agreed to serve as the on-site coordinator for the *Vecinos y Rehabilitation: Phase II* project. His first act as the on-site coordinator was to meet with key government officials and decision makers, health care educators, community service representatives and indigenous people with disabilities who could potentially serve on the PAC, as well as offer the support of the agencies with which they were associated. In addition, the co-investigator, George Gotto, made a trip to Huajuapan de León in February, 1996 in order to assist with the development of the project. Together, Mr. Galicia García and Mr. Gotto met with four different agency leaders within the city of Huajuapan de León to discuss the project and ask for official support.

Once the survey instrument was finalized and the training of the interviewers had been completed, it was administered to 140 indigenous people with disabilities from rural areas in the Mixteca region, as well as within the city of Huajuapan. The people who administered the survey instrument were themselves indigenous people with disabilities who were members of ADM.

Results of Phase I and Phase II

During Phase I of the project (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996), a total of 232 individuals with disabilities were surveyed in three different geographic regions of Oaxaca; specifically, the *Capital* [City of Oaxaca], the *Mountains* [Miahuatlán], and the *Coast* [Puerto Escondido]. The majority [69% (161)] of these respondents lived in the *Capital*, with 20% (46) living in the *Mountains*, and 11% (25) living on the *Coast*. During Phase II of the project (Marshall, Gotto, & Galicia García, 1998), a total of 140 indigenous people with disabilities were interviewed in both *Urban* (Huajuapan) and *Rural* areas in the Mixteca region of the state. Two-thirds of these individuals were from *Rural* areas [66% (93)] with the other third being from *Urban* [34% (47)] areas.

Results from both studies, including analyses of quantitative as well as qualitative data, indicated that there was a great need for education, rehabilitation, and employment. Of concern was the lack of education among adult respondents with disabilities, as the majority from both phases of the research reported that they either had no education, or not more than a grade school/primary level education. Given this finding, however, it is not surprising that the majority of those persons with disabilities who were unemployed were also those with no education. Perhaps most stunning was the finding that the **majority of school-age children with disabilities were not attending school**.

As regards access to rehabilitation services, assistance in Mexico, as in the United States, appears to be more available in urban areas than in rural areas. For example, in Phase I of the project, while the majority of respondents in the urban capital of Oaxaca reported receiving some form of rehabilitation or financial assistance, only 13% of the respondents from the rural *Mountains* received such assistance.

None of the respondents in Phase II of the project from either urban or rural areas reported receiving any type of rehabilitation or financial assistance. Rehabilitation as a profession is unknown in Mexico; vocational rehabilitation services for adults do not exist. Thus any reference to rehabilitation most often means medical rehabilitation or physical therapy. However, the comments of respondents indicated that there is great interest among people with disabilities, and among their family members, for the development of community education programs, for family education programs, and for vocational rehabilitation.

In terms of employment, while the majority of adult respondents from Phase I of the research were employed, this number included seasonal workers, sustenance farmers [*campesinos*], and part-time workers. Only 24% (22) of the adult respondents in Phase II of the research were employed. According to one grassroots leader of people with disabilities in Oaxaca, it is rare indeed to find a person with a disability who has a full-time job with benefits, especially in rural areas (Ing. Rigoberto Mendoza Bohorquez, personal communication, October 26, 1995). It is important to note that the majority of adult respondents who were employed were men with disabilities; just over a third of adult women with disabilities from Phase I of the research were employed, compared to over 50% of the men. Only 27% (16) of the adult men from Phase II of the research were employed but this was still a higher percentage than for the adult women [19% (6)].

Action agenda. Partly as a result of the collaborative research conducted in Oaxaca by AIRRTC researchers and *Acceso Libre* staff and volunteers, *Acceso Libre* received a grant from the W. K. Kellogg Foundation that allowed them to develop *El Centro de Rehabilitación Integral,* a consumer-driven nonprofit organization. El Centro, among other activities, focuses on the rehabilitation, education, and employment of indigenous persons with disabilities in and around Oaxaca City, as well as outreach to rural indigenous communities (see Marshall, Gotto, & Galicia García, 1998, Appendix A). The results of the research project in the Mixteca region were presented to the PAC members, one member of which was the Mayor of Huajuapan de León. The mayor was so concerned with the lack of resources available to people with disabilities that he immediately allocated funds to begin a rehabilitation program in Huajuapan de León.

Assessing Needs and Resources in the Mixe Region (Phase III)

Castañeda (1995) has described Mexico as "a country of three nations: the *criollo* [Spanish or white] minority of elites and the upper-middle class, living in style and affluence; the huge, poor, *mestizo* [mixed white and Indian] majority; and the utterly destitute minority of what in colonial times was called the Republic of Indians--the indigenous peoples of Chiapas, **Oaxaca**, Tabasco, Michoacán, Guerrero, Puebla, Chihuahua, and Sonora, all known today as *el México profundo*: deep Mexico" (p. 38). The concept of "utterly destitute" can be, in part, understood from an economic perspective. Using data from the 1990 Mexican census, Castañeda (1995) reported that "63.2 percent of the nation's inhabitants made no more than twice the minimum wage--$200 per month--while price levels approached those in the United States" (p. 51). **According to data taken from the 1990 Mexican census (Bazúa**

Rueda, 1997), there are 5,282,347 indigenous people (over age 5) who speak their native language living in Mexico. Of these more than 5 million individuals, the plurality, or 1,018,106 live in Oaxaca, followed by 716,012 who live in Chiapas. Of the more than 1 million indigenous people in Oaxaca who speak their native language, slightly more than half (521,651) are women (Bazúa Rueda, 1997).

According to a recent document distributed by the U.S. Department of Education (Briefing, 1991), "from its inception, NIDRR has been active in international research of benefit to the U.S. and to other Nations." *Vecinos y Rehabilitation: Phase III* has continued the promotion of linkages between American Indians with disabilities in the United States and indigenous people with disabilities in Oaxaca, Mexico through documenting the needs and resources of the Mixe in Totontepec Villa de Morelos, Oaxaca. Linkages revolve around accessibility issues, culturally-relevant rehabilitation needs, and building on the dynamic relationship between Mexico and the United States. Thus, the purpose of *Vecinos y Rehabilitation: Phase III* was to:

1. Establish the feasibility of conducting major research and training projects involving indigenous people with disabilities in a **remote, rural community**, that is, Totontepec Villa de Morelos, Mixe (pronounced *Me-hay*), Oaxaca, Mexico.
2. To continue to develop a program of information exchange between Mexico and the United States involving experts in the field of rehabilitation and Native peoples.

In both the United States and Mexico, service providers struggle to appropriately serve persons in rural areas, in particular, people from indigenous backgrounds, as the indigenous people in both Mexico and the United States are culturally and philosophically extremely different from the dominant society in their respective countries. Comments from one indigenous leader with quadriplegia, director of the *Instituto Comunitario Mixe* (Mixe Community Institute), and on-site research coordinator for *Vecinos y Rehabilitation: Phase III*, Mr. (Ing.) Juan Arelí Bernal Alcántara, illustrate this point (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996; see also, same citation, Appendix C, for complete text of Mr. Bernal Alcántara's comments; see Appendices A and C of this report for more information about the Mixe):

> We think that what the government wants are international plans where there are no Native people, where we are all the same, but we are not all the same; the truth is we are not all the same. Our language, our culture, is not taken into consideration. Each individual who is educated in the [majority] community always says: *my* car, *my* house, *my* office, *my* family. In contrast, the patterns in the Native communities are *our* town, *our* party, *our* work, *our* . . . . It's a little different, you know, to speak in the plural form than to speak in first person (p. 88).

The Indian people of Oaxaca have long been studied by anthropologists (see, e.g., Greenberg, 1989; Nolen, 1973; Parsons, 1936), archaeologists, (see, e.g., Bronkington, & Long, 1974; Flannery, & Marcus, 1983), and ethnologists (see, e.g., Chance, 1989; Cook, & Borah, 1968). Oaxaca has a rich cultural background and diverse indigenous traditions. The indigenous people represent approximately 19% of the total population and are comprised of 17 ethnic groups (Lipp, 1991). The ethnic, or indigenous, groups of Oaxaca have struggled to maintain their culture, language, and traditions given the great pressure from the mestizo culture and the massive influence of the radio and television. The geographic location of Oaxaca makes it very difficult to reach the 7,200 small ethnic communities scattered throughout the state, where they have their own standard of living and their own traditions (Lipp, 1991). These small communities have to live with a dual economy, determined both by their traditions and by the outside world.

METHODS

Researchers from the AIRRTC have spent over a decade assessing the needs of American Indians with disabilities on a nationwide basis. For nearly 15 years, AIRRTC research has been focused at the local community level, and has included American Indian people with disabilities throughout the research process--from design, to instrument development, to data collection, to dissemination. This philosophy of directly involving Indian people with disabilities in the research process guided the procedures of this project (see, e.g., Bruyère, 1993).

A linkage to the Mixe region was initially made through the first phase of our *Vecinos y Rehabilitation* research (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996). One of the primary objectives of this research project was to "establish the feasibility of conducting major research and training projects involving indigenous people with disabilities in Mexico." In an effort to accomplish this objective, the PI, Dr. Catherine Marshall, made a trip to Totontepec Villa de Morelos, Mixe, Oaxaca in October, 1995. It was on this trip that Dr. Marshall initially met with Mr. (Ing.) Juan Arelí Bernal Alcántara, director, *Instituto Comunitario Mixe.* The *Instituto Comunitario Mixe* is a grassroots organization that is dedicated to the preservation of the Mixe culture and the education of the Mixe people.

Research Questions

1. What are the needs of indigenous people with disabilities in rural and remote communities in Oaxaca, Mexico? What research methodology is best suited to assessing their needs?

2. What specific rehabilitation technologies currently employed successfully in rural Mexico can be of benefit to American Indians with disabilities, especially those living on rural and remote reservations? To what extent can technologies successfully utilized in the United States by people with disabilities in rural areas be exported to Mexico?

Participants

According to Lipp (1991), the Mixe "population consists of some 76,000 individuals distributed among fifty villages and many more hamlets" (p. 1). Specifically, "The Mixe live in the northern part of Oaxaca, on the border of Veracruz, comprising what until 1971 was the Mixe District. . . . The *Ayuuk* or Mixe are in fourth place among native speakers in Oaxaca following the Zapateca, Mixteca, and Mazateco" (Los Mixes, 1997, p. 3).

Reyes Gómez (1995) has explained that "The Mixes call themselves *Ayuuk jä'äy*. The language that they speak is *ayuuk* which is also a historical name for the group. The word *ayuuk* comes from *a* = language, word; *yuuk* = mountain, with flowers; and *jä'äy* = people, crowd. For this reason, the meaning is people of floral language." (p. 5). Reyes Gómez further explained that "The *ayuuk* region has been divided in three regions according to the weather: high or cold . . ., medium elevation or warm . . . and low elevation or hot . . . . The region has a total of 19 districts: the cold region includes Tlahuitoltepc, Ayula, Cacalotepec, Tepantlali, Tuxtepec, **Totontepec**, Tamazulpam y Mixistalán" (pp. 6-7, emphasis added). Finally, "In 1969 bilingual education was introduced in the region; this included alphabetization in the native language and Spanish as a second language" (Reyes Gómez, 1995, p. 7).

The following has been written in regard to the Mixe (*Ayuuk*) perspective on health and their health concerns (Reyes Gómez, 1995):

> The Mixes believe health is the result of equilibrium and harmony, good behavior, as well as the respect for the prehispanic and Christian deities. Among the *Ayuuk* there are three types of sickness: 1) Natural origins as indigestion and constipation, 2) Supernatural illnesses as the result of the loss of equilibrium between men, nature, and society (examples of these illnesses are "sorcery," "sadness," sickness acquired while sleeping, etc.). If the person suffers from this kind of illness, s/he requests the help of their own medicine man or woman, and 3) Ailments with the well-defined causes, as the chronic alcoholism, addition to tobacco, and drug addiction. The most common illnesses that affect the Mixe are: respiratory infections, tonsillitis, intestinal infections, amoebae, and ascariasis. These illnesses become serious due to a high rate of malnutrition among this ethnic group (pp. 10-11).

Totontepec Villa de Morelos

The town of Totontepec Villa de Morelos, in the Mixe region of Oaxaca, Mexico served as the target site for this project due to its population of indigenous people and the willingness of Mr. (Ing.) Juan Arelí Bernal Alcántara to serve as the on-site research coordinator. Because Totontepec is a small town, the on-site coordinator knew of the people with disabilities. The criteria used to identify persons as having a disability were at least one of the following: they had a visible physical or psychological problem, were deaf, and/or could not speak. Even though it was understood that there were many health problems that could result in a disability, persons were *not included* in the study who did not have medical references for their health problems, or whose problems were not visible, for example, people with diabetes.

According to the 1990 national census (XI Censo, Tomo [Vol.] II, 1991) there are 1,018,106 people over 5 years old in the state of Oaxaca who speak an indigenous language. For example, 319,000 speak Zapoteca, 237,474 speak Mixteca, 146,928 speak Mazateco, and 88,863 speak **Mixe**. The town of Totontepec has a total population of 5,394, with females constituting 51% (2,747) of the population and males constituting 49% (2,647) of the population (XI Censo, Tomo [Vol.] I, 1991). The number of people older than 5 years in Totontepec is 4,583 (XI Censo, Tomo [Vol.] II, 1991). From this group, 4,396 (96%) speak an indigenous language (Mixe = 4,281 [97%]; Zapoteca = 73 [2%]; Chinanteco = 6; Zapoteco del Istmo = 1; unspecified = 35). There are 170 (4%) people in Totontepec who are older than 5 years who do not speak an indigenous language; of this group 84 (49%) are younger than 15 years old. Among all of the people in Totontepec who are older than 5 years, 3,436 (75%) speak Spanish. In terms of religion, among people older than 5 years, 2,766 are Catholic and 1,608 are Protestants (XI Censo, Tomo [Vol.] II, 1991). Of persons age 15 or older (3,001), there are a total of 1,199 (40%) who can not read (XI Censo, Tomo [Vol.] II, 1991). In terms of employment, many of the men (1,119) are agricultural workers and the women who have work (161) are classified as professionals (XI Censo, Tomo [Vol.] VIII, 1991). Of persons age 15 or older, 28 (1%) reported being "permanently handicapped" in regard to work (XI Censo, Tomo [Vol.] VII, 1991).

The above review of the literature regarding the Mixe was based on scholarly, published texts. However, the authors would also like to include the observations of the on-site coordinator, who is Mixe, lives in Totontepec, and thus has first hand knowledge about the Mixe way of life. The remaining sections of "Participants" were contributed by the on-site coordinator, Juan Arelí Bernal Alcántara, in an attempt to provide a context for understanding the villagers of Totontepec.

Indian Nations of Mexico

Mexico is a mosaic of Indian nations, each possessing its own territory, language, religion, traditions and culture, whose history extends back thousands of years. Many of these cultures left behind great monuments, many of which have already been discovered, and some of which are yet to be discovered. In some cases, these are colossal works which tell of a past full of splendor. These nations gave origin and special characteristics to the Mexican Republic, laying the foundations of the nation's culture.

The advanced level of development of some of these nations awakened the greed of the European colonizers. They came in search of riches and, in their passing, destroyed very important cultural and scientific treasures. During a 500 year period, the Europeans tried to destroy these nations. Frequently, they were successful.

A clash of cultures this strong brought with it many negative consequences, some which are actually still reflected in current problems such as:

- Discrimination
- Social Isolation/Marginalization
- Theft of Lands
- Extreme Poverty
- Immigration

- Illiteracy
- Exploitation

The defense mechanisms implemented by Indians, because they are so firmly rooted in their traditions, have allowed 56 indigenous nations to continue to survive throughout Mexican territory. In the state of Oaxaca, there are 16 indigenous groups which still follow many of their traditional practices and customs. The Mixe form the fourth largest indigenous population in the state, after the Zapotecos, Mixtecos, and Mazatecos.

The total indigenous population is 5,282,347 according to data provided by the National Institute of Statistics, Geography and Information (INEGI) in 1990. This only includes children over five years of age. This total equals 6.5% of the national population. Table 1 shows the indigenous groups and the states in which they live; it is believed that two times as many Indians actually exist but are uncounted. The inaccuracy of these figures is a result of immigration both within and outside of the country, and because of discrimination. Many prefer to hide their Indian origin in order to avoid greater discrimination, and INEGI also admits to having excluded five Indian nations. We may conclude that 20% of the total population is indigenous, or approximately 20 million.

Ayuuk Jaa'y–The Mixes

The Mixe people are settled in the southern part of Mexican territory, with the majority in the northeast of the state of Oaxaca and others in the southern part of the state of Veracruz. The census of the INEGI, in 1990, reported a population of 95,264, but we believe there are approximately 150,000 Mixe, including children under the age of 5 and Mixe who have immigrated to other cities or countries. Of the 150,000 total, 25% live in

Table 1

Indigenous Population by Nation and State

Indigenous Nation	States	Population
Amusgo	Guerrero and Oaxaca	28,228
Cochimi	Baja California	148
Cora	Nayarit	11,923
Cucapa	Sonora	136
Cuicateco	Oaxaca	12,677
Chatino	Oaxaca	28,987
Chichimeco jonaz	Guanajuato	1,582
Cinanteco	Oaxaca	109,100
Chocho	Oaxaca	12,677
Chol	Chiapas	128,240
Chontal	Oaxaca and Tabasco	36,267
Chuj	Chiapas	NA
Guarijio	Chihuahua	NA
Guasteco	Hidalgo, San Luis Potos' Veracruz	120,739
Huave	Oaxaca	11,955
Huichol	Jalisco and Nayarit	19,363
Ixcateco	Oaxaca	11,955
Jalcalteco	Chiapas	1,263
Kakchiquel	Chiapas	436
Kikapú	Coahuila	232
Kiliwa	Sonora	41
Kumiai	Baja California	96
Lacandón	Chiapas	104
Mame	Chiapas	13,168
Matlatzinca	State of Mexico	1,452
Maya	Campeche, Quintana Roo and Yucatan	713,520
Mayo	Sinaloa	37,410
Mazahua	State of Mexico	127,826
Mazateco	Oaxaca and Veracruz	168,374
Mixe	Oaxaca and Veracruz	95,264
Mixteco	Guerrero, Oaxaca and Puebla	386,974
Motocintleco	Chiapas	235
Nahuatl	State of Mexico, Guerrero, Jalisco, Michoacán, Oaxaca, Puebla and Veracruz	1,197,328

Table 1

Indigenous Population by Nation and State

(continued)

Indigenous Nation	States	Population
Otom'	State of Mexico, Hidalgo, Puebla and Veracruz	280,238
Pai Pai	Baja California	223
Pame	Queretaro and San Luis Potos'	5,732
Pápago	Sonora	NA
Pima	Chihuahua and Sonora	860
Popoloca	Oaxaca	NA
Popoluca	Veracruz	31,254
Purépecha	Michoacán	94,835
Seri	Sonora	561
Tarahumara	Chihuahua	54,431
Tepehua	Veracruz	8,702
Tepehuan o Tepecano	Durango and Nayarit	755
Tlahuica u Ocuilteco	State of Mexico	68,483
Tojolabal	Chiapas	36,011
Totonaco	Puebla and Veracruz	207,876
Triqui	Oaxaca	14,981
Tzeltal	Chiapas	261,084
Tzotzil	Chiapas	229,203
Yaqui	Sonora	10,984
Yuma	Baja California	26
Zapoteco	Chiapas and Veracruz	403,457
Zoque	Chiapas and Veracruz	43,160
Other indigenous languages		18,421
Insufficiently specified		225,860
TOTAL		**5,282,860**

Note: NA = Not Available

Mexico City, the city of Oaxaca and abroad. Those living abroad are mainly illegal immigrants. Those who immigrate generally maintain contact with their villages of origin, contributing money for the development of their towns or belonging to groups that help their native communities. Generally they return for the fiestas and continue having the same rights and responsibilities as citizens.

The municipality of Totontepec, where the study was done, is located in the northeast section of the Mixe region and has a population of 6,500 persons. The municipality is made up of 11 villages, and the research was carried out exclusively at the municipal seat which has 1,800 inhabitants.

Totontepec is 1,860 meters (1.2 miles) above sea level, and has a very humid, temperate climate (an average rainfall of 4,000 millimeters, or 157 inches) with many foggy and cloudy days. The vegetation is a mesophyllous mountain forest. There are highways, electricity, public telephones, a kindergarten, a nursery school, two elementary schools, a tele-site [distance learning] middle school, a high school, and a community institute for the preservation and development of the culture, in addition to a rural health clinic. There is bus service twice daily at 6:15 a.m. and 11:40 a.m. to Oaxaca City, which is 160 kilometers (99 miles) away. [However, road conditions make this trip a 5–7 hour journey by bus.]

Origin and history. The origin of the Mixe is unknown. There are three main theories concerning the roots of this people: the first states that they came from Europe, proposed by Father José Antonio Gay in 1883; the second states that they came from Peru, in migrations which began in the year 1200, approximately, in search of the sacred mountain of Cempoaltepetl (mount of 20 peaks or divinities). This theory is from Dr. Sánchez Castro, in 1948.

The third theory, that we come from the Olmecas, is the most viable one in the view of the author of this text, and for the following reasons:

- The geographical proximity of the Olmeca sites in southern Veracruz and Tabasco, in addition to the fact that the Olmeca culture gave birth to many Mexican cultures.
- The pattern of settlement in Mixe territory, which indicates a migration from southern Veracruz and part of Tabasco in search of a higher mountain, sacred for them since they are coming from plains at sea level.
- The family of the Mixe language, comprised of Zoque, Mixe and Popoluca, forms a crescent around the Olmeca sites.
- The name of the Mixe in our language is *ayuuk jaay,* an evolution from the word *ayujk* which means "above," so that the translation would be "the people who live above" or "the people of the mountain" since their ancestors lived on the plain.
- Archeological remains discovered, which are similar to Olmeca figures and were found on routes in the direction of the eastern part of the region, leading to Veracruz and Tabasco.
- There are oral legends in Totontepec and the town of Huitepec that indicate that we come from the southern part of Veracruz.

The Mixe nation, located on the skirts of Cempoaltépetl, was characterized as a warring people since before the arrival of the Spaniards, which allowed them to possess their current territory. Dedicated to agriculture, hunting, fishing, and war, their development was not marked by the creation of large architectural monuments, which could tell us about the past, although there are some relics in the municipality of Totontepec that have not yet been studied.

The Mixe had a head chief called Kong Oy who lived in Totontepec, from where he could control all of the Mixe villages in their constant battles with the Zapotecos. The historical aspect which stands out most about this head chief is that he was never defeated, and for this reason he is seen as a symbol of freedom and valor by all of the Mixe. He made a name for himself in the battles against the Zapotecan king, Zachila I, who had allied himself with the Mixteco people in order to defeat the Mixe. After several failed attempts to conquer the Mixe, the army of Zachila I army set fire to Cempoaltépetl, and according to legend, Kong Oy took refuge in a cave where he still lives, in order to reunite the Mixe nation.

The Mixe also fought against the Aztecs around the year 1500, when the Aztecs wanted to take sand and stones from the Mixe to use to sharpen their weapons. The Aztec ambassadors were killed, and Montezuma was infuriated by this, and went to fight the Mixe. Several battles were waged in Quetzaltepec and Jaltepec, and the fact that the Aztecs did not return to Tenochtitlán with Mixe slaves shows that they did not win these battles (Gay, 1883); the victory is attributed to the Mixe.

In 1521, they confronted the Spaniards, but due to the difficult entry to the territory, the Spaniards were unable to bring their horses and canons into the region, and hence were unable to conquer by force; they were limited to building a fort on January 23, 1531, in the town of San Ildefonso, Villa Alta, to the west of Totontepec, with the goal of stopping the Mixe. From Villa Alta, the Dominican missionaries set out, instilling the Roman Catholic religion in the Mixe, founding their first parish and monastery in Totontepec in 1572.

The Dominicans created schools and controlled education, which was characterized by religion and catechism, until the year 1700. The Dominicans distinguished themselves by learning the Mixe language, and since that time writings in Mixe have existed, mostly prayers and religious texts written by Father Augustín Quintana. Around 1712, the Dominicans left the area, and the Diocesans arrived in their place, continuing the evangelization of the region until 1963, when the Salesians arrived.

The Mixe, because they had not been taken by force, almost did not partake in the Mexican war of independence. The Mexican revolution did not affect the life of the Mixe people, because Mixe participation in the war was very little, due to their great distance from the places where the fighting occurred. Some of Carranza's armies did arrive. The revolutionaries were satisfied with the provision of food supplies, so they withdrew peacefully.

The internal history of the Mixe was influenced more by the *cacique* [Indian chief, political boss], Luís Rodríguez of the Zacatepec Mixes, because of all the atrocities that he committed in his continuous assassinations and exploitations of other villages' riches, in conjunction with the public officials of the Mixe district of Zacatepec, over a 30 year period starting in 1930.

In recent years, the work of the Salesian monks has influenced much of the development of the Mixe, Chinantecos, and Zapotecos. They created schools and worked so that some of the Mixe could leave in order to become educated, so that they might return as leaders in their communities and work to preserve and develop the Mixe culture.

Language. The Mixe language is one of the languages that have humanizing and agglutinative characteristics. That is, almost everything relates to the human body and various ideas are bound together in only one word. The Mixe language belongs to the Zoque-Mixe-Popoluca family. Zoque is spoken in Tabasco, close to the border of Oaxaca and Veracruz. Mixe is primarily spoken in the northeast of the state of Oaxaca. Some Mixe villages are also found in the southern part of Veracruz. Popoluca is spoken in Puebla and Veracruz, in adjacent regions.

The Mixe language has its variants according to the villages' varying distances and altitudes above sea level. This can be clearly seen in the number of vowels used. In the lower section they only have six vowels, one more than in Spanish. In the middle section they generally use seven vowels, or two more than in Spanish. In the upper section they use eight vowels, or nine as in the case of Totontepec, perhaps the only municipality that uses nine vowels. This is most noticeable in the municipal seat. Perhaps this is due to a faster evolution of the language [at the lower elevation levels] because of earlier and more constant contact with the Spanish language, in the attempts of the Spanish conquest since November of 1521.

With the opening of mass communications (highways, radio, television and Spanish textbooks), there has been a tendency towards a decreased use of Mixe, mostly among children and young people. Even the parents are interested in their children speaking more Spanish. The families with less access to the outside through travel or contact with people are those that speak the Mixe language more. Those with professions--generally educated in the city--speak Mixe, but rarely do they transmit it to their children, because of the tendency to speak more in Spanish. The young people do not value the native language and they resist studying it, because they say that they already know it.

The Mixe language is spoken much more than it is written; in other words, we find few bilingual books or books written in the Mixe language. This problem exists because of many reasons. One reason is that the type of education available is only given in Spanish. Another reason is because of the government policy of cultural homogeneity throughout the entire population. In addition, in Mexico there is a preference for that which is foreign, because it is thought that things which come from the outside are better than those that already exist here. This situation puts the existence of the Mixe in danger, as a cultural group with its own language and view of the world. The fact that the existence of their language is in danger also means that a national cultural treasure is in danger of being lost as well.

There is a strong potential of being able to read and write the Mixe language because of the existence of the following symbols (see Tables 2–4). The existence of the symbols is the result of a consensus among participants of the whole Mixe region, which included the three areas determined by altitude, and was carried out by the Regional Commission of the Ayuuk language. They have been working on this for about eight years and have been studying the already existing alphabets as well as meeting with experts and groups involved with the Mixe language.

The *Vecinos Project* was conducted in the Totontepec community, so we show the nine vowels used in the village, as well as giving examples of each one. With this information, we hope to make it possible to read and understand some words and ideas that we will be working with in this text. This symbol (') is considered a consonant as it causes a long vowel to be cut. The cutting of the vowel causes the pronounciation to be glottalized as in the following words: *be'em* [yes], *ka'a* [no], *pe'et* [to sweep], *xi'ik* [to laugh], *ya'axy* [to cry], *poo'p* [white], *pö'ts* [yellow].

Table 2

Abaatspa—Vowels

"a"	as in	ap—grandfather ak—skin, peel or shell an—heat or hot
"e"	as in	ets—dance eex—crab mex—boy
"i"	as in	ix—to see it—land mix—young boy or child
"o"	as in	ok—grandmother on—butter kox—knee
"u"	as in	tun—to work uts—younger brother or sister muk—together
"ä"	as in	äp—shade or shadow kääm—pig (animal) kääts—crag
"ë"	as in	ëets—I ëm—uncle nëk—paper, documents
"ö"	as in	ök—dog ööx—a fly nööx—lazy
"ü"	as in	üb—to sing küp—stick, tree pük—to take, a prize, to marry, to hunt

Table 3

Atojkpa—Consonants

"p"	as in	pak—dove, old (object) pen—to squeeze pet—to go up, a rise	NOTE: This symbol becomes "b" if it is preceded by m, n.
"t"	as in	tek—foot taak—mother toots—tongue	NOTE: This symbol becomes "d" if it is preceded by n or m.
"k"	as in	kakky—tortilla kay—to eat kaan—salt	NOTE: This symbol becomes "g" if it is preceded by m or n.
"j"	as in	jäp—there is jäm—there jok—smoke	This consonant is very common with the aspiration occurring after the short or long vowels and together with any other consonant.
"m"	as in	meen—money mook—corn mëkk—strong, tough	
"n"	as in	naax—land nëëj—water, liquor num—to run	
"ts"	as in	tsëk—to want tsuk—to cut tsaaj—stone	
"x"	as in	xöoxpa—music (from wind instruments) xöx—cold xux—to be cold out	
"y"	as in	yëk—black yën—long, tall or high yam—today	NOTE: "y" becomes palatized when followed by: b, k, d, g, j, m, n, p, t, ts, x.

Table 3

Atojkpa-Consonants

(continued)

“b”	as in	bëp—to beat bit—clothing bidët—to go for a walk
“d”	as in	madëts—stick maaydëk—to chat, story, history töödöjtëk—eight
“g”	as in	mugoock—five agats—people not of the Mixe race, Zapotec, or Chinantec töögupx—sixty

Table 4

Consonants Borrowed from Spanish

“l”	as in	loro	[parrot]
		azul	[blue]
“r”	as in	aro	[hoop]
		oro	[gold]
		hora	[hour]
“s”	as in	oso	[bear]
		base	[base]
		sopa	[soup]
“f”	as in	foco	[focus]
“ ’ ”		glottal	

For the Mixe, all the feelings and moods of a person come from the stomach *[joot]*, so in order to express one's mood, there is always a reference to the stomach. In order to understand the Mixe culture better, the following list of 35 Mixe words, with their meanings and literal translations, has been compiled from the different possible moods of a person (see Table 5). It should be noted that the literal translation of the Mixe word(s) into English does not fully convey the Mixe meaning.

Table 5

Mixe Word Meanings

Word	Meaning	Literal Translation
aaj joot	to be	mouth stomach
ajoota	to fancy something	to feel it in the mouth and stomach
ayooba mjoot	threat	poor in your stomach
baamp njoot	yes I want	if my stomach says so
dûtsokût njoot	yes I want	if my stomach wants
jotbimbit	to feel affection from	to return the stomach
jotküda'aky	to heal	to lower stomach, (a settled stomach)
jotküx	to be exhausted	to finish the stomach
jotmay	worried	many stomachs
jotmaya	to miss	multiplied stomach
jotma'aty	to be angry	bad-tempered stomach
joymay jèêtp	pregnant in engagement	between many stomachs
jotmë'ë	to give trust	to give stomach
jotmêk	of strong character	strong stomach
jotmën	forgetful	distracted stomach
jotmööstk	of feeble character	small stomach
jotmubopa	to make a mistake	to hit yourself in the stomach
jotnaa'kon	very aware	joined at the stomach
jotpää'ty	to understand	to find stomach
jot'bij	to wake up	wide-awake stomach
jot'xoondük	enthusiastic	contented stomach

Table 5

Mixe Word Meanings

(continued)

Word	Meaning	Literal Translation
jot'ambüküj	to be seriously angry	to begin to overheat one's stomach
jot'amëj	satisfied or calm	big stomach
jot'anyjü	to be angry	burning stomach
jot'it	satisfied for a long time	to stay in the stomach
jot'ix	to put to the test	to see stomach
jot'oya	to be content	composed stomach
joot'ja'bin	spirit	spirit stomach
kä'a mjoot mjapükjü	to like something	your stomach doesn't hurt
kopk'joot	spirit of the mountain	mountain stomach
küx joot	each time more and more	stomach finish
mäjts joot	lack of sincerity	two stomachs
nyünmékkjoota	to dominate oneself	hard stomach
tök joot	sincere	one stomach
xonduuk'joot	happily, with pleasure	happy stomach

__Political and territorial division.__ The Mixe territory extends over an area of 4,668.55 square kilometers (1,802.53 square miles) between 16 degrees 15' and 18 degrees 10' latitude and between 95 degrees 14' and 97 degrees 52' of longitude west of the Greenwich Meridian. It is composed of 19 municipalities in all; only two of the municipalities do not belong to the Mixe district: San Juan Guichicovi is in the District of Juchitán and San Juan Jaquila Mixe is in the district of San Carlos Yautepec. Guichicovi has the district seat of Juchitán much closer, that is why it does not belong to the Mixe district; in the case of San Juan Juquila Mixes, it does not belong to the Mixe district for political differences of exploitation and the dominance of Zacatepec over this municipality.

The Mixe District was created in 1938 by President Lázaro Cárdenas and is the only one at the national level that brings together a specific ethnic group. This District, with its seat in Zacatepec Mixe, is composed of 17 individual municipalities (see Table 6).

The territory encompassed by the Mixe is divided into zones according to the altitude above sea level. The lower zone, from 150 meters to 1300 meters; the middle zone from 1300 to 1800 and the upper zone from 1800 up to 3396 meters at the top of Cempoaltepetl, the highest mountain, and its ceremonial site of preference.

There are other small villages that are Mixe which belong to other municipalities, mainly Zapoteco municipalities, such as in the case of Tonaguía with the Municipality of Royaga in the District of Villa Alta and the same is true of 10 other villages. We can say that they are about 180 villages, including the municipal seats, according to the criteria which indicate what is a village or just a group of houses.

Table 6

Municipalities with *Agencias* and Hamlets

Municipality	**Name in Mixe**	**Zones**	**Number of Villages**
Atitlán	Neba'ap	middle	8
Ayutla	Tök öyum	middle	5
Alotepec	Ne'eb okum	middle	2
Cacalotepec	Jëë'köjm	middle	4
Cotzocón	Cotsüko'm	lower	24
Camotlán	Müntsäp	middle	1
Incuintepec	Ökükubajkum	lower	1
Juquila Mixes *	Kë'ën Kë'm	middle	4
Mazatlán	Amajktstüo'am	lower	17
Mixistlán	Epüts küxp	upper	7
Ocotepec	Tüüxkë'm	middle	2
Quetzaltepec	Kon'äätsum	middle	3
Tepantlali	Kummujkp	upper	3
Tlahuitoltepec	Xää'm këxm	upper	6
Totontepec	Anyu'kojm	middle	10
Tepuxtepec	Pux këjxm	upper	8
Tamazulapan	Tö'k nëm	upper	8
Zacatepec	Mëkyëxm	middle	3
Guichicovi * *		lower	24
TOTAL			**140**

* Belongs to the District of San. Carlos Yautepec
* * Belongs to the District of Juchitán

Economy. The foundation of the economy is the land surrounding the community, which is dedicated mainly to agriculture and livestock, but some communities also harvest lumber. In the agricultural sector, the principal activity is the harvest of corn for self-consumption; people in the middle and lower zones cultivate coffee, using it for self-consumption and commercial exportation. Coffee, which is the main crop, brings in most of the money for the family budget and is marketed to coffee monopolies, generally Zapotecos and some Mixe, who in turn sell it to companies with the task of exporting it.

The family garden or orchard is quite common in the cool and semitropical regions, and includes avocados, peaches, vegetables, bananas, and citrus fruits; all are used for self-consumption.

Raising livestock is common, mostly in the middle and lower zones. In the upper regions, livestock is kept and used for pulling and hauling, both in agriculture and as beasts of burden, since many villages and fields are not accessible by car/truck.

The family is at the forefront of the work force, and the entire family plays a role in maintaining the home. The work of the children is very important in the fields. The woman's job is generally inside the home, and also includes the manufacturing of handicrafts and artisanry such as coats, blouses, and pottery, in some towns.

Health. Good health for the Mixe is to be *"mëk tsot"* [strong and healthy]. These two words are specifically referring to health; this means that one does not have any sickness. The perfect state of a person is *"oy yakxon mëk tsot"* [completely well, healthy and strong], which is the result of being in harmony with:

a) With God [*Nte'yam*]
b) With the universe [*it naxbiijn* = sky, earth]
c) With nature [*kopk kääts nëëj töö* = mountain, crag, water, path]
d) With the community [*kajpün*]
e) With those in authority [*kajpün niteniba*]
f) With one's body and spirit [*jyoot, jyabin*]
g) With the dead or ancestors [*ap ok* = grandfather, grandmother]

With God. This means keeping *mandas* [religious promises or vows] or religious duties.

With the universe and nature. This means one has kept all of the rites and sacrifices to the universe and to the mother nature, making an offering in one's daily life of a little of one's drink or food, praying the following:

> *"mits it naxbiijn, kopk kääts, nëëj töö' chajada mjë'ë pëkta tönda maayin"* [You sky, earth; mountain, crag, water and path, may you have what is yours; receive it, please.]

On special occasions one goes to make sacrifices, or offerings are taken to altars, temples or ceremonial sites in each community, whether it be the new year or the undertaking of a new endeavor or some journey. Roosters or turkeys are sacrificed and tamales, *tepache* [beverage made from an unripened pineapple], mezcal, *pulque* [alcoholic beverage], cigarettes, or bundles of thirteen *ocotes* [branches] are offered. The ceremonial site preferred by all Mixe is Cempoaltepetl, the sacred mountain, with an altitude of 3,396 meters (approximately 11,117 feet). For this reason one must never anger or curse at the earth because one's spirit may be absorbed and stay in that place.

With the community and those in authority. This means one honorably and responsibly keeps the duties which are conferred upon him by the people or those in authority. The honorability involved in keeping the duties is acquired by offering a fiesta, with food for the entire village, when one receives the charge or when it is one's turn according to the traditional fiestas of the community, and in addition one must perform the duty well.

With the body and the spirit. This is not to feel any pain in the body and to have a healthy bodily or spiritual universe located in the stomach [joot].

In harmony with grandparents and ancestors. This is kept by celebrating their fiesta on November 2, the day of the dead, making their altars and bringing offerings (tamales, bread, fruits, and liquor) so that the ancestors will come on that day, will eat, and will feel pleased and remembered.

Not being in the harmony with these seven elements of the universe and life, means one can lose one's health. When talking specifically about health, there are three states of health in the Mixe conception that also determine physical appearance:

a) *Mék tsot* [strong and healthy]. This is to be very well, without any pain or illness, having the ability to work and carry out any activity.

b) *Kanatiö' ktsotap, ma'at* [not being completely healthy, not functioning]. It is every person who has a defect or a physical limitation, as a result of an accident, a consequence of an illness, congenital, or superstitiously attributed. In this category, chronic degenerative illnesses or old age are not included.

c) *Pëjjup* [sick]. Refers to a person who is sick, especially those that are bedridden, including the chronic degenerative illnesses, old age and those with mental affects. This category includes people with physical limitations, who are bedridden due to lack of care or knowledge.

The Mixe possess a great wealth of expressions to describe the symptoms of illnesses, possibly due to the great concern they have about their physical condition, and at the same time giving orientation for possible cures (see Table 7). Traditional Mixe medicine offers the possibility for persons

Table 7

Illness Symptomology

Ailments	Translation
any	to burn
atsu’ux	to annoy, bother
bi’its	occurrence of the ailment likened to small blows from a rod
bii’t	to tighten specific places
bëx	sharp rhythmic pain
bimpikmuk	stomach cramp
bingaa’tmuk	a bite
binbëë’nmuk	to pull, joining two parts of the body
jaj	to irradiate
kum	to pierce, to puncture
ka’mmuk	sudden bite
muk	shrinkage, contraction
nitip	cold or tremors
niximkapy	chills
pük	to hurt
pa’amyj	diffuse pain
tukju’up	lash from a whip
tukyükx	to pierce like with an ice pick
tsu’uts	to itch (as in it itches)
uu’kx	with the least intensity than (yë’ëts)
xö’xuba	falling asleep of the body
yo’oy	to stir, move around (under the skin)
yë’ëts	to pierce in various places simultaneously

with disabilities to be cured of some specific ailments (having been tried by the author of this section), which, in some cases, bring together physical treatments and the use of medicinal plants at the same time.

For example, *temazcal* is a very dry steam bath, used since prehispanic times to cure many ailments. It consists of a small, well-enclosed room made of adobe and wood (may also be brick), making a small vault for a roof (like a small bread oven), with a small entrance and a place to heat up the stones next to the room, called *xuu'tsk*, with the approximate dimensions being one meter high [approximately 3 feet 3 inches], one and one-half meters wide [approximately 4 feet 10 inches], by two meters long [approximately 6 feet 6 inches]. The temazcal bath is excellent for reducing and correcting contractures of muscles or bones, improving blood circulation, and eliminating toxins through sweat. The process consists of heating the stones well, at the same time heating the small room, and when the highest level of heat is reached the patient and the assistant enter, either nude or with a bathing suit, with their respective bundle of fresh, green branches of elderberry, eucalyptus, peach, or pepper trees. Inside there must be a water receptacle with a bowl; one begins by pouring a little water on the rocks and immediately starting to apply the branches to the patient with light strikes. One continues to add more water to the heated rocks depending on how much the patient can withstand and one will continue to apply the branches, striking the entire body, face up and also face down; the process lasts from 15 to 30 minutes.

The treatment for persons with contractures is from five to eight sessions or more, depending on the extent of need, and may be daily or spaced out every other day according to what the patient can withstand. It is very necessary that patients with high blood pressure first do test runs with less heat inside the temazcal, because they may have problems with the high temperatures. Another precaution that should be observed is not to expose oneself to drafts of air after leaving the temazcal and not to bathe oneself with cold water during the treatment period.

Medicinal plants cure many illnesses, but in this case we want to highlight one illness common among persons with disabilities which is kidney stones, gallstones or other kinds of stones. To avoid or combat this kind of problem it is recommended to take an infusion (tea) of a combination of three plants: *Cola de caballo (Equisetum arvence), pinguica* and *hierba del sapo* (*Eryngium spp*). For 10 minutes a large spoonful of the mixture of these three herbs is boiled in a liter of water; it is taken hot, on an empty stomach, one or two hours before meals, or as a drink at room temperature, without salt or sugar.

The *aje* is a wax produced by a tropical yellow wasp which warms the muscles when it is applied, and may be used for massages and body rubs when there is an injury in the bones or muscles, including broken bones and cuts.

On-site Research Coordinator

As with any AIRRTC community-based research project, one of the first priorities was to hire an indigenous on-site research coordinator. Because of the previous contact with Mr. (Ing.) Juan Arelí Bernal Alcántara, because he was the director of the *Instituto Comunitario Mixe*, and because he had extensive contacts with the local community, as well as with community leaders in Totontepec, he was asked to be the on-site research coordinator. Further considerations in hiring Mr. (Ing.) Bernal Alcántara included that he is Mixe, has quadriplegia, and is bilingual in Mixe and Spanish.

At the time when he was initially contacted in 1995, Mr. (Ing.) Bernal Alcántara was not able to participate as an on-site research coordinator due to health problems. However, as his health improved, Mr. (Ing.) Bernal Alcántara began to participate in the *Vecinos y Rehabilitation* projects. In December 1995, he attended and participated in a conference in Oaxaca City that was sponsored by the AIRRTC, *Acceso Libre, Dirección General de*

Desarrollo Social [General Administration of Social Development], *Frente Unido de Minusvalidos* [United Front of People with Disabilities], and *Unión de Mujeres Discapacitadas* [Union of Women with Disabilities] (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996). At this conference, he presented a paper referred to earlier in this report and entitled "Preservación de la Cultura Mixe y el Idioma de Santa María Totontepec" [Preservation of the Mixe Culture and Language of Santa María Totontepec] (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996, Appendix C). In this paper, he discussed the differences between the majority culture in Mexico and the Mixe culture, as well as the importance of preserving indigenous cultures in Mexico.

In March 1996, Mr. (Ing.) Bernal Alcántara traveled to Tucson, Arizona, where he attended a conference on indigenous people with disabilities in the United States and Mexico. Following this conference, he traveled to Flagstaff, Arizona where he had the opportunity to meet with researchers and administrators at the AIRRTC (see Appendix B). Mr. (Ing.) Bernal Alcántara also traveled to Albuquerque, New Mexico where he attended a national meeting of the Consortia of Administrators for Native American Rehabilitation (CANAR). Most recently, Mr. (Ing.) Bernal Alcántara attended and participated in a conference sponsored by the AIRRTC and ADM in Huajuapan de León, where he gave a presentation regarding Mixe concepts of health and well-being (see Appendix C) and chaired a roundtable discussion on education (Marshall, Gotto, & Galicia García, 1998, Appendix I).

Project Advisory Committee

One of the first tasks that Mr. (Ing.) Bernal Alcántara undertook as the on-site research coordinator was to develop the Project Advisory Committee

(PAC). There were four people who agreed to serve as members of the PAC that would assist researchers in finalizing the design of the project, finalize the instrumentation, and plan for the dissemination of the results. These four members were: Raquel Rivera, a nurse at the community health center; Ester Chavez, a mother and housewife; Braulia Reyes, a naturopathic healer in the community; and Adrian Rojas, a farmer with a disability.

Instrumentation

Quantitative Data

The survey instrument that was used for this research project was based on the instruments that were developed by the research teams for the *Vecinos Projects: Phase I and Phase II.* Dr. Marshall and Mr. Gotto presented a final draft of the survey instrument in Spanish to the on-site coordinator and other members of the research team in Totontepec for their consideration at a meeting in Totontepec on March 18, 1997. The on-site coordinator and the local research volunteers suggested changes to the questionnaire. Following their suggestions, changes were made to the instrument in order to make it culturally appropriate to the Mixe people. As a result of suggestions from the PAC, as well as the on-site coordinator, the survey instrument was translated into the Mixe language (see Appendix D).

Qualitative Data

A structured, open-ended interview protocol was developed in order to obtain qualitative data regarding the needs of persons with disabilities (see Appendix D). Questions were developed from a previous AIRRTC qualitative study (Marshall & Cerveny, 1994), with review by the on-site coordinator, as well as Mr. Pedro Flores Rey, Director of Services and

Programs, *El Centro de Rehabilitación Integral*. Persons with disabilities were asked questions about their needs, the meaning of "disability," services that were offered to them, and their fears for the future; similarly, family members were asked about their needs, the needs of their family member with the disability, the meaning of "disability," and their fears for the future (see Appendix D).

Interviewer Training

During their trip to Totontepec in March, 1997, Dr. Marshall and Mr. Gotto conducted an interviewer training session (see, e.g., Marshall & Johnson, 1990) with three volunteers from the community (including one PAC member) and the on-site research coordinator. Mr. Ovaldo Galicia García, on-site research coordinator for *Vecinos y Rehabilitation: Phase II*, assisted in the training by sharing his experiences in using the questionnaire in the Mixteca region. The purpose of the four-hour training session was to teach the interviewers how to interview objectively and record responses accurately. Topics that were covered in this training session included confidentiality, the influence of the interviewer on the investigation, and the responsibilities of the interviewer (Interviewer training guide is available upon request from the AIRRTC).

Data Collection

Quantitative Data

Prior to the interviewer training, Mr. (Ing.) Bernal Alcántara went before the Totontepec city council and the mayor to explain the project to them and solicit their support. They approved the project and wrote letters in the names of each of the interviewers authorizing them to carry out the research (see Appendix E). The project interviewers carried this letter with them to their interviews to demonstrate to the respondents that the project had been reviewed and approved by the city council and mayor, adding credibility and authority to the research project.

Beginning in May, 1997, the local interviewers began surveying people with disabilities in order to identify and assess their needs. Because Totontepec is a relatively small community, an attempt was made to conduct a census study in terms of interviewing all persons who had an identifiable disability. The on-site coordinator and the local interviewers knew or were able to identify 64 people in their community who had a disability. Following each interview, the interviewer would ask the respondent if he/she knew anyone else within Totontepec who had a disability. The interviewers would then contact the recommended individuals and ask if they were interested in responding to the questionnaire. All of the respondents to the survey were Mixe people with disabilities. All interviews were completed by July 31, 1997. The completion date of these interviews was later than had been originally anticipated due to heavy rainfalls, during which the interviewers were not able to complete interviews.

Qualitative Data

Dr. Marshall and Mr. Gotto conducted six ethnographic interviews with Mixe people with disabilities between the dates of March 18, 1997 and March 21, 1997. In addition, six family members of people with disabilities were interviewed. The 12 interviews were recorded on video and/or audio tape, and were conducted in Spanish with the use of a Mixe translator, when necessary.

Data Analysis

Quantitative Data

Following the collection of the quantitative data in Totontepec, the completed surveys were sent to the AIRRTC researchers in the United States. The quantitative data were entered into *SPSS for Windows* (1994) and then analyzed using the same program.

Qualitative Data

The analysis of the qualitative data began with the transcription of the interviews and the subsequent translation of the interviews from Spanish to English. Both of these tasks were completed by staff at the Translation Center which is based out of the University of Massachusetts in Amherst. The translated data were then analyzed using *The Ethnograph* (Seidel, Kjolseth, & Seymour, 1988). This is a menu driven program that allows the researcher to organize, code, and review the qualitative data much faster than would be possible if this were done manually. Five of the six family interviews corresponded to the six individual interviews conducted with people who had disabilities; only these five family interviews were included in the data analysis.

Community Meeting

Following the data analysis, a community meeting was held in Totontepec. The primary purpose of this meeting was to report the results of the research to the people with disabilities and their family members who participated in the project. A second reason for the community meeting was to give the people with disabilities in the community a forum for developing an action plan for the future that outlined steps that they could take in order to have their needs addressed. To supplement this process, disability advocates and rehabilitation professionals were invited to the meeting to give presentations about the work that they have done in other indigenous communities. For example, Anna Johansson, Director of Piña Palmera, a rehabilitation center for children with severe disabilities that is located in southern Oaxaca, gave a presentation about her program. In addition, Ela Yazzie-King, a Navajo woman with a disability and a disability advocate in the United States, gave a presentation about her experiences as a person with a disability on the Navajo reservation.

RESULTS

Quantitative Data

General Overview

A total of 64 people with disabilities from the Mixe district responded to the survey. All respondents were living in Totontepec at the time of the survey. The vast majority of respondents were originally from Totontepec [96% (62)]; one person (2%) was from San Miguel Metepec and one person (2%) was from La Candelaria. All of the respondents reported that their ethnicity was Mixe. The majority of the respondents spoke the Mixe language [94% (60)], 52% (33) of the respondents spoke Spanish, 3% (2) spoke English, and two persons (3%) were babies not yet speaking. The preferred language among the majority of the respondents was Mixe [83% (52)]. A small percentage of the respondents [12% (8)] preferred to speak Spanish and one person (2%) preferred to speak an unspecified language.

The majority of the respondents were female [58% (37)] with the remaining 42% (27) of the respondents being male. The range of ages among the respondents was from six months to 92 years old. The average age was 45 years. For the purpose of analysis, respondents were categorized as *adults* (15 and older) and *children* (14 and younger). (The justification for classifying *adults* as "15 years and older" was that 15 years was the accepted working age in the state of Oaxaca). The majority of respondents were adults [83% (53)], with children making up 17% [11] of all respondents. A large majority of the respondents [70% (45)] reported that they were dependent on another person.

The most common cause of disabilities among the survey respondents was congenital problems [37% (24)]. Illnesses were the cause of 30% (19) of the disabilities and accidents caused 30% (19) of the disabilities. Two respondents did not report the causes of their disabilities. As Table 8 demonstrates, the most common disability among all respondents was poor vision [33% (21)]. Arthritis [17% (11)] and "muscular dystrophy" (any type of muscle weakness; any type of muscular degeneration) [16% (10)] were also common among the respondents. Table 8 also shows that a large number of the respondents reported that they had a disability other than those listed on the survey. Some of these other disabilities were hunchback, club foot, mentally delayed, blood clots, nervousness, and cleft palate. The areas of the body that were affected by the various disabilities were, among others, vision [45% (29)], hearing [20% (13)], speech [17% (11)], brain [16% (10)], and lower limbs [16% (10)]. The greatest needs among the 64 respondents were medical attention [59% (38)], family support [52% (33)], physical rehabilitation [34% (22)], and health [19% (12)]. The vast majority of the respondents [95% (61)] reported that they did not have access to disability related services.

Table 8

Disability/Pre-condition of Respondents

Disability/Pre-condition	%	# *
Poor Vision	33%	21
Arthritis	17%	11
Muscular Dystrophy (any muscle weakness; any muscular degeneration)	16%	10
Blindness	11%	7
Deaf	11%	7
Congenital Malformations	9%	6
Epilepsy	8%	5
Developmental Disability	8%	5
Autism	3%	2
Hemiplegia	3%	2
Paraplegia	3%	2
Quadriplegia	2%	1
Infantile Paralysis	2%	1
Other	30%	19

*Note: N of responses = 99; some of the 64 respondents had more than one disability.

The last question on the survey instrument asked the respondents if they had any additional comments. The comments that were made focused primarily on the needs of the respondents. The need that was mentioned most often was medical attention. For example, one respondent said, "Medical attention because I need medicine. Also, a health and rehabilitation center because there aren't any in this area." Another person said, "Medical attention and medicine because if you are healthy and strong you are happy." Many of the respondents mentioned either economic support or employment. One respondent said, "Economic support in order to resolve my health problems." Another respondent commented, "Economic support so that I can buy what I need to live." In terms of employment, one respondent said, "Many don't have work and they live on very little and I believe that we need a source for work." One participant linked education with work, "An education that prepares you for a job so that afterwards you have economic resources and can then live a better life." Some respondents reported that they needed things as basic as food, clothing, and shelter. For example, one person said, "Help to cure the people who are sick and help with clothing and food. Also, help those who don't have a house to find one." Another person said that he needed "family support, clothes and food."

Adult vs. Child Comparisons

Adults

Of the 64 people who responded to the survey, 83% (53) were adults. Among the adults, there were more women [57% (30)] than men [43% (23)]. The average age of the adults was 53 years, with a range in age between 15 and 92 years old. Many of the adults were single [43% (23)]; a smaller number of the adult respondents were either married [30% (16)], widowed [23% (12)], or had another type of relationship [4% (2)]. At the time of the interviews, all of the adult participants were living in Totontepec. The majority of the adults were born in Totontepec [96% (51)]; one person (2%) was born in San Miguel

Metepec and one person (2%) was born in La Candelaria. All of the adults were Mixe and spoke the Mixe language. In addition, almost half [49% (26)] of the adults spoke Spanish. One of the adults (2%) spoke English. Even though nearly half of the adults were bilingual, the majority [87% (46)] preferred to speak Mixe; 11% (6) of the adults preferred to speak Spanish, and one adult did not indicate a preference.

The majority of the adult respondents [55% (29)] reported that they did not have dependents. In contrast, 64% (34) of the adults reported that they depended on another person for their food and clothing. The average number of dependents, among the 38% (20) of adults who reported having dependents, was 2.45. As Table 9 displays, a small majority of the adults [53% (28)] reported that they had no formal education and a little over a third of the adults [38% (20)] reported that they had at least some grade school (primary school) education. The one person (2%) who reported having a

Table 9

Education Level of Adult Respondents

Education Level	%	#
No Education	53%	28
Grade School	38%	20
Middle School	4%	2
High School	4%	2
Professional	2%	1

professional education was an agricultural engineer. Nearly three-quarters of the adult respondents [74% (39)] reported that they did not have an income. The remaining 26% (14) of adult respondents said that they received an income through employment [24% (13)] or a pension [2% (1)]. Those people who were employed had jobs such as administrators, farmers, maids, seamstresses, or masons. Only one (2%) of the adults who was employed had a full time job with benefits. Of the 13 (24%) adults who were employed, 11 (85%) felt that they were treated well at work. However, the majority of the adults who were employed [92% (12)] reported that the money they made at their jobs was not enough to satisfy either their daily needs or their disability related needs.

A little over a third of the adult respondents [34% (18)] reported that their disabilities were congenital. Another 34% (18) of the adults said that their disabilities were caused by illnesses and 28% (15) said that they had a disability due to an accident. The remaining 4% (2) of the adults did not report the cause of their disability. Table 10 demonstrates that given those adults who had poor vision [32% (17)] and those who were blind [11% (6)], nearly half of the adults had a vision impairment. Other common disabilities among the adults were arthritis [21% (11)], "muscular dystrophy" (any type of muscle weakness; any type of muscular degeneration) [13% (7)], and deafness [13% (7)]. Table 10 also shows that many of the adult respondents had a disability other than those that were listed on the survey [26% (14)]. Some of these disabilities included hunchback, blood clots, nervousness, and cleft palate. The areas of the body that were most commonly affected by the disabilities were, vision [45% (24)], hearing [23% (12)], lower limbs [17% (9)],

Table 10

Disability/Pre-condition of Adult Respondents

Disability/Pre-condition	%	# *
Poor Vision	32%	17
Arthritis	21%	11
Muscular Dystrophy (any muscle weakness; any muscular degeneration)	13%	7
Deaf	13%	7
Blindness	11%	6
Congenital Malformations	9%	5
Epilepsy	7%	4
Developmental Disability	6%	3
Autism	4%	2
Hemiplegia	4%	2
Paraplegia	2%	1
Quadriplegia	2%	1
Infantile Paralysis	2%	1
Other	26%	14

*Note: N of responses = 81; some of the 53 adult respondents had more than one disability.

and speech [11% (6)]. The vast majority of the adult respondents [94% (50)] reported that they did not have any resources available to them that could help them with their disabilities. The three remaining adults reported that they had access to private institutions [2% (1)] or other resources [4% (2)].

As Table 11 demonstrates, the most pressing need among adults with disabilities was medical attention [55% (49)]. In addition, the adults reported that they were in need of family support [49% (26)], physical rehabilitation [26% (14)], health [17% (9)], and employment [15% (8)]. Many of the adults

Table 11

Needs of Adult Respondents

Area of Need	**Percent of Individuals % (#)**		**Percent of Responses* %**
Medical Attention	55%	29	24.8%
Family Support	49%	26	22.2%
Physical Rehabilitation	26%	14	18.2%
Health	17%	9	7.7%
Employment	15%	8	6.8%
Capacitation	9%	5	4.3%
Education	7%	4	3.4%
Psychological Support	2%	1	.9%
Other	40%	21	17.9%

*Note: N of responses = 117; some of the 53 individuals had more than 1 need

[40% (21)] reported that they had some needs other than those that were listed on the survey. Some of these needs that were most commonly mentioned were money, food, medicine, and housing.

Children

A total of 11 children (14 years and younger) with disabilities responded to the survey. The majority of these children were girls [64% (7)], with boy's making up 36% (4) of the group. The ages of the children ranged from 6 months old to 14 years. There were six children with disabilities who were old enough to attend school (6 years and older). Of these six children, one third had no education [33% (2)], one third had attended grade school [33% (2)], and one third had attended middle school [33% (2)]. Each of the children were Mixe and lived in Totontepec. The majority of the children spoke both Mixe [73% (8)] and Spanish [64% (7)]. Two children were babies not yet speaking. The majority of the children (or their representative) [64% (7)] said that Mixe was their first language and 18% (3) said that Spanish was their first language.

The majority of the disabilities among the children were congenital [55% (6)]; 36% (4) were caused by accidents and 9% (1) were due to illnesses. The average number of years that the children had their disabilities was 6 years. As Table 12 indicates, the most common disability among the children was poor vision [36% (4)]. The areas of the body that were most commonly affected by the disabilities were vision [45% (5)], speech [45% (5)], and the brain [45% (5)]. All of the children (or their representative) reported that there were no disability related services available to them. Table 13 demonstrates that the two most pressing needs for the children with disabilities were medical attention [82% (9)] and family support [64% (7)].

Table 12

Disability/Pre-condition of Child Respondents

Disability/Pre-condition	%	#*
Poor Vision	36%	4
Muscular Dystrophy (any muscle weakness; any muscular degeneration)	27%	3
Developmental Disability	18%	2
Congenital Malformations	9%	1
Epilepsy	9%	1
Blindness	9%	1
Paraplegia	9%	1
Infantile Paralysis	9%	1
Other	45%	5

*Note: N of responses = 19; some of the 11 child respondents had more than one disability.

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Table 13

Needs of Child Respondents

Area of Need	Percent of Individuals % (#)		Percent of Responses* %
Medical Attention	66%	7	26.5%
Family Support	64%	7	20.6%
Physical Rehabilitation	55%	6	17.6%
Education	55%	6	17.6%
Health	27%	3	8.8%
Information	18%	2	5.9%
Other	40%	21	17.9%

*Note: N of responses = 34; some of the 11 individuals had more than 1 need

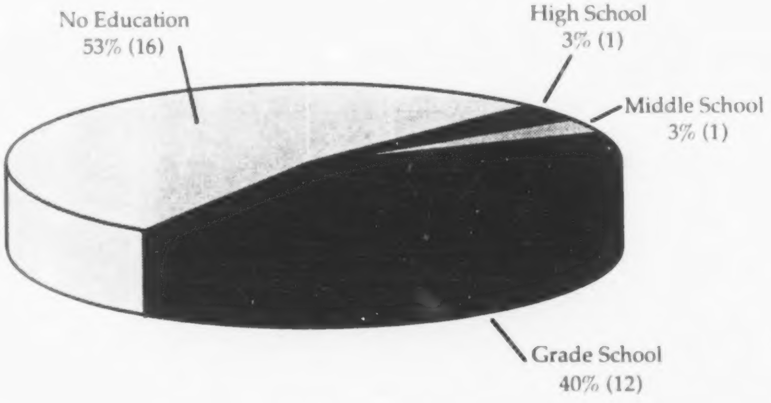
Women vs. Men Comparisons

Women

A total of 30 women responded to the survey. Their ages ranged from 15 to 92 years with the average age being 50 years. A large percentage of the women [43% (13)] were 60 years old or older. A majority of the women were single [53% (16)]; 23% (7) of the women were widows, 20% (6) were married, and 3% (1) reported another type of relationship. All of the women were Mixe and resided in Totontepec. One of the women did not report which languages she spoke; however, 97% (29) of the women reported that they spoke Mixe. In addition, 47% (14) of the women spoke Spanish. The majority of the women said that their preferred language was Mixe; 7% (3) preferred to speak Spanish and one (3%) did not report her preference.

Figure 1 illustrates that the overwhelming majority of women [93% (28)] with disabilities either had no education or only a grade school education. Only 13% (4) of the women reported having an income. All of these women received their income through employment. Each of these women worked part-time as seamstresses or maids. Three of the four women reported that they were treated well by their employers, but one reported that she was not satisfied with the way that she was treated. All of the employed women reported that their incomes were not enough to meet their living expenses or their disability related needs. Almost a quarter of the women [23% (7)] reported that they had an average of 1.6 dependents. In contrast, 83% (25) of the women reported that they were dependent on another person for their living expenses.

Figure 1
Education Level of Women with Disabilities
(N=30)



The most common cause of disabilities among the women was congenital problems [40% (12)]. Accidents were the cause of 30% (9) of the disabilities and illnesses caused 23% (7) of the disabilities. Two of the women (7%) did not report the cause of their disabilities. The majority of the women [93% (28)] said that there were no disability related services available to them in Totontepec. However, two (7%) women said that they had access to private institutions or other unspecified services. The most common disability among the women was poor vision [33% (10)], followed by arthritis [23% (7)]. Other disabilities not listed on the survey included [30% (9)]: problems with knees, mentally delayed, nervousness, and blood clots. The areas of the body that were most commonly affected by disabilities among the women were vision [53% (16)], hearing [23% (7)], speech [17% (5)], and lower limbs [17% (5)] (see Table 14).

Table 15 demonstrates that the most pressing needs of the women with disabilities were family support [50% (15)], medical attention [50% (15)], physical rehabilitation [27% (8)], and health [20% (6)].

Men

A total of 23 men with disabilities responded to the survey. The average age of these men was 56 years old, with a range of 16 to 91 years. The majority of these men [83% (19)] were between 40 years and 91 years of age. A plurality of the men [44% (10)] were married, 30% (7) were single, 22% (5) were widowed, and 4% (1) reported another type of relationship. All of the men were Mixe and spoke the Mixe language. In addition to Mixe, some of the men spoke Spanish [33% (12)] and English [3% (1)]. Mixe was the preferred language for 83% (19) of the men. The remaining 17% (4) preferred to speak Spanish. The majority of the men were from Totontepec [91% (21)];

however, one man (4%) was from San Miguel Metepec and another was from La Caudelonio (4%).

Table 14

Disability/Pre-condition of Women Respondents

Disability/Pre-condition	%	# *
Poor Vision	33%	10
Arthritis	23%	7
Blindness	17%	5
Muscular Dystrophy (any muscle weakness; any muscular degeneration)	17%	5
Congenital Malformations	10%	3
Developmental Disability	10%	3
Epilepsy	7%	2
Deaf	7%	2
Autism	3%	1
Hemiplegia	3%	1
Paraplegia	3%	1
Other	30%	9

*Note: N of responses = 49; some of the 30 women had more than one disability.

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Table 15

Needs of Women with Disabilities

Area of Need	Percent of Individuals % (#)		Percent of Responses* %
Medical Attention	50%	15	23.1%
Family Support	50%	15	23.1%
Physical Rehabilitation	27%	8	12.3%
Health	20%	6	9.2%
Employment	10%	3	4.6%
Capacitation	10%	3	4.6%
Education	7%	2	3.1%
Psychological Support	3%	1	1.5%
Other	40%	12	18.5%

*Note: N of responses = 65; some of the 30 individuals had more than 1 need

A majority of the men reported that they had no education [52% (12)] and 35% (8) said that they had no more than a grade school education. One man (4%) had no more than a middle school education, one (4%) had a high school education, and one (4%) had professional training. The majority of the men [57% (13)] reported that they did not have an income. Those men who did have an income received it through employment [39% (9)] or through a pension [4% (1)]. Those men who had employment worked as farmers, masons, waiters, or administrators. Only one of the men (an administrator) worked full-time and received a full benefit package. Among the men who worked, most [80% (8)] felt that they were treated well at work. Only 20% (2) of the men who worked said that their income was enough to meet their living expenses and their disability related needs. A majority of the men [57% (13)] reported that they had an average of three dependents. In contrast, 39% (9) of the men were dependent on someone else for their living expenses.

As Figure 2 indicates, almost half of the mens' disabilities [48% (11)] were caused by illnesses. On average, the men had their disabilities for 23 years with a range between 5 and 60 years. Table 16 demonstrates that

Figure 2
Origins of Disabilities Among Men
(N=23)

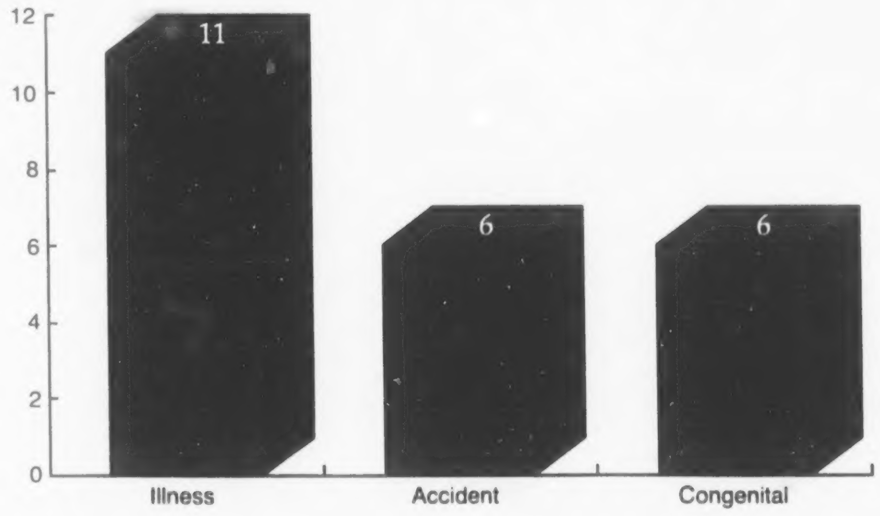

Table 16

Disability/Pre-condition of Men Respondents

Disability/Pre-condition	%	# *
Poor Vision	30%	7
Deaf	22%	5
Arthritis	17%	4
Muscular Dystrophy (any muscle weakness; any muscular degeneration)	9%	2
Congenital Malformations	9%	2
Epilepsy	9%	2
Blindness	4%	1
Quadriplegia	4%	1
Autism	4%	1
Hemiplegia	4%	1
Other	22%	5

*Note: N of responses = 31; some of the 23 men had more than one disability.

considering both blindness and poor vision, over a third of the men [35% (8)] had a vision impairment. Other common disabilities among the men were deafness [22% (5)] and arthritis [17% (4)]. Table 16 also demonstrates that a large percentage of the men [22% (5)] had disabilities other than those that were listed on the survey. Some of these disabilities were hunchback, problems with knees, and mentally delayed. The areas of the body that were

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most commonly affected by the mens' disabilities were vision [35% (8)], hearing [22% (5)], and the lower limbs [17% (4)]. Only one (4%) of the 23 men said that he had access to disability related services. He received this service from an unspecified institution. The most pressing needs for the men were medical attention [61% (14)], family support [48% (11)], physical rehabilitation [26% (6)], employment [22% (5)], and health [13% (3)].

Qualitative Data

Definition of Disability

People with Disabilities

Each of the six people with disabilities who responded to the ethnographic questions were asked to explain the meaning of "disability" from the Mixe perspective. The respondents gave two different types of responses to this question. The first type of response was that there was no word for disability in the Mixe language. For example, one respondent simply said, "There is no such word in Mixe." Another respondent gave a more lengthy description, "From the Mixe perspective, we do not have a culture of disability, specifically. In my case, people think that it is a big misfortune, a serious illness, they see it as a misfortune. . . . " This person went on to say:

> *That was the concept at the beginning. Now they see me like a broken person. But not as the term is used for a machine that does not work. Instead as a physical limitation, that is what broken means in Mixe. To be clear, first it is a misfortune, a big misfortune. Second, now that they see me here and there, and that I am involved in many activities they may think, "He is a broken person but he is doing something else. . . ."*

> *When they see results on the job, they may say, "He is broken but he is doing things. We accept you, there is no problem."*

The second type of response acknowledged that despite the lack of a word for disability in the Mixe language, illnesses or conditions existed that limited the life activities (such as work) of a person. One respondent, when asked to explain the meaning of disability, said, "A person who can not fight for his/her own life, someone who can not earn a living. For example, me. In the past I worked, but not anymore since I am disabled. I can not work, not even to earn a penny. . . . If there is no family, how are we supposed to get our food? Whom are we going to get support from? Thank God I have my spouse, at least to help me eat." Another respondent gave a similar description, "According to my own point of view, disability is when you are limited to do a job. It is when my body does not respond when I need to perform a task. You are disabled when you have to perform a task but your body can not respond."

Specific types of disabilities, as described by research participants or by the Mixe translator, included:

> *She is not able to walk since she can not see.*

> *My limitation is that I can not walk; I can not move well enough my arms. I do not feel my fingers; I can not move them. I do not feel anything from my chest to my lower extremities, which brings many physiological consequences. My disability consists of not being able to walk, not to feel my legs, moving partially my arms, not to move or feel my fingers, not to able to have a complete respiration.*

> *My illness is a very long never-ending history. First, I started having pain in my knee. Around here, you do not go to the doctor, you let the illness progress, hoping it will go away by itself. When you are poor you can not go to the doctor promptly because there is no money. I started having pain in my knees, but I continued working. . . . Then my whole body was in pain.*

> *My physical disability consists of not being able to lift heavy objects as other persons do. It limits me. I have had two operations and that is what limits me. . . . It was because of the operations that I can not lift heavy objects. Otherwise I feel like something is ripping inside of me. I also have a tumor or a kind of arthritis in my right hand--I have pain. . . .*

> *He said that it hurts a lot and he can not move. His hand is totally paralyzed and he can not move it. He can not move; it takes a lot of effort. He can not walk or move like we do. He only walks by using a cane* (translator).

> *My whole body contracts. There is pain when I walk, when I move. When I lay down there is a deep pain if I turn around. . . . It is my whole body, from head to feet. . . . I have been like this for nine years.*

Family Members of People with Disabilities

The family members of the people with disabilities were also asked to explain the meaning of disability from the Mixe perspective. Their answers were similar to those of the people with disabilities. For example, the family members reiterated the idea that there was no word for "disability" in Mixe.

One family member said, "We did not know that was how they are called. Now we know that the ones who can not walk and the ones who have suffered an accident are called disabled." Two of the family members who were interviewed said that they felt sad about the disabilities that their family members had. One family member said, "It makes me sad but there is nothing else that can be done." Finally, another family member defined "disability" as an illness. She said, "The people who are sick or who need something. That is what I think about." She continued, "around here there are many people with disabilities. . . . Some are hereditary problems; others are caused by lack of food or lack of care during childhood."

Services Available

People with Disabilities

The people with disabilities who responded to the ethnographic questions indicated that there were no services in Totontepec that were tailored specifically for people with disabilities. One person who was asked what services were available to people with disabilities in Totontepec said, "There is no such thing around here. I have not seen any type of activity or rehabilitation in this area. We are forgotten." When this same person was asked what a person with a disability in Totontepec did if they needed rehabilitation, he replied, "Then you have to go somewhere else. Places such as Oaxaca (City) where you know there are the services needed for your problem or your disability."

Even though all six of the respondents said that there were no services for people with disabilities in Totontepec, some did acknowledge that there was a medical center in town. However, they felt that it was for conditions such as broken bones or childbirth. One of the respondents believed that rehabilitation equipment would soon be available. He said, "There are other types of services such as medicine, for people who need medical assistance of another type. But specifically for people with disabilities, there is nothing. Just recently, rehabilitation equipment was brought in but it is not working yet. It is brand new and the nurse is being trained."

Family Members of People with Disabilities

In terms of services available in Totontepec to assist with disability, one family member commented simply, "If we are really sick and we want to survive, we have to go to Oaxaca. Around here there are not enough medicines nor enough specialists so we have to go to Mexico City or to Oaxaca." Another family member said, "Nobody cares about the needs of people with disabilities. Only God knows how we manage to support them."

Effect of Disability

Persons with disabilities were asked to talk about the ways in which disability had affected their lives. They talked about the frustration of wanting to work, wanting to succeed, wanting to take care of their families, but not being able to do any of these things as a result of their disabilities. The passages below are excerpts from the answers that were given by four of the respondents which illustrate the effect that their disabilities have had on their lives in the rural and remote town of Totontepec.

> *It does affect me a lot. It affects me since we are on our own. I do not have anybody else. Being here, I can not prosper. I can not do what I want to, which is work, prosper, get money so I and my mother can prosper. She is also sick and can not work. She is sick and I am sick. . . . [I want] to have a job and to be healthy in order to work. Otherwise, how can you work if you are not healthy. What I yearn for the most is*

to be healthy, to have a job, and to succeed. Not being healthy affects me a lot. If I was healthy, I could work a lot in Mexico City and, even earning so little, I would still send some money here.

My body hurts. If I sit down I get better. But if I stay sitting down for more than two hours my whole body contracts and I can not move anymore. It is even worse when I lay down, then I can not move. That is why it's very hard. . . . Everything changes. It is only through God that I am living. I am not even able to wash a dish. If I do not have someone (to help), I can not live like a normal person. Everything is difficult. My girl does some things. She makes tortillas, but she can not wash clothes since she is too little for that. However, she can now wash dishes.

That it is a limitation to do things. In my case, I used to be healthy, to be completely well. I had many plans. I used to do a lot of exercise, I used to be very involved in my town. Now I have to think that many things can be done but it has to be another person who does them because I can not go there. Now, I depend on another person for things to be done and that makes me impatient. It does make me feel impatient because I know many things can be done but someone else has to do them. And who knows if it will meet the criteria of the taste the person who has to do them. That is what limits me, that I know many things can be done but it has to be by someone else. That is my big problem. I say to myself, "many things can be done and should be done." And I can think about it but there should be someone else to do them. And that is precisely the great problem, who knows if that

> *person really wants to do it, if I will have any money to pay that person well enough, or if that person can really solve a problem when it comes. That is a limitation, like a mental limitation to my life, my town.*
>
> *I was 19 years old when I first realized I had a bone tumor on my left foot. It was very hard. With time it became worse, it aggravated. In 1974 I needed an operation. With the help of the Salecianos [a Catholic religious order], I went to Oaxaca where I had the operation. After a year, I went back to work. Later, six years ago, I had another problem on my genitals and I needed another operation. It was precisely then when my problems started again. Before the operation and during the following two years I did not work. That meant not earning any money but I needed that time to recuperate. . . . It worries me because I can not do jobs that require strength. I have to look for a job I can do. It worries me a lot because of my family. I had another plan but it changed because of the operation I had. I have struggled in looking for any type of jobs. It is my duty, as a father, to work to support my children. I have to work in order to succeed.*

Work

Persons with disabilities were asked if they had a job in their community. Most of them indicated that they either did not have work or that they had part-time work. Their comments demonstrated that they wanted to work, that they had worked in the past, but because of their disabilities and their lack of education, they were not able to work currently. However, regardless of disability, it was generally acknowledged that due to its rural and remote location, there were not many salaried jobs in Totontepec. For example, one person with a disability commented, "Around here, there are only poor peasants. We only grow corn and beans around here. When there is a good harvest it is OK, otherwise we are in trouble." Similarly, a family member commented,

> *Around here there are no jobs. The truth is that there are no jobs and that is why they go somewhere else. . . . That is why they go to Mexico City. Or they go to the United States as wetbacks, hiding, because they do not have money. Around here it rains a lot. Sometimes people work, but as soon as the rain season comes everything is over. In the past, there used to be cane and aguardiente [alcoholic beverage] to sell. But there is no aguardiente anymore so people have to move somewhere else.*

Another of the respondents with a disability said,

> *I think about succeeding, and hoping the wind will take this illness away. I think about finding a job because around here there are no jobs. I like this place a lot; it is beautiful, but there are no jobs. Around here there is no such a thing as a job, as succeeding. . . . By being healthy, you can work anywhere you want. If there were some jobs around here, I could also work here. . . . I [have] worked as a maid. This is my job since I did not have any higher education. By having education, you can work in something else.*

When asked if he had a job in the community, one respondent said,

> *Not precisely, because I did not have the opportunity to learn an occupation. For our people, working in the field is the most important one; then it is not necessary to get an education. You learn to work while you are in the cornfield. . . . Sometimes I work unloading heavy*

> *rocks from trucks. I can work for a while but after a while I get exhausted.* [He continued] *As a father, I really have to work hard for my children. Who knows what they will like to do in the future? You can hope things would get better, but that will depend on the education they will get.*

Another of the respondents commented, "In the past, when I was healthy, I did not go to school. I am not trained for any specific job. Instead, I worked cleaning houses, ironing and washing clothes, or cooking for someone else. I got paid for doing that." One respondent reported having a lot of work, but did not receive a salary:

> *I do have plenty of work. First, because I am part of a community, I have the consciousness of being part of a population, that I am part of my community and that my duty as any other citizen is to contribute, to help in the development of our people, our village. Then, having that consciousness, one should be involved in many activities, not necessarily because you will be paid for them. I always have a lot of work. I am in charge of [a] project . . . and that by itself is a job. But if another thing comes up, if someone asks for my help, I will be there. Or, if I see the need for something or if there is a problem and it can be solved, I go for it. That is why I am involved in many activities. It is not because of a salary, but because one is part of a community, part of a town and one should do something for the development. And also because it hurts me so much that there is a problem and nobody does anything. So I should participate an try to organize, to see how it can be solved. In that sense, I have a lot of work.*

Each of the six respondents were also asked how their disability affected their ability to work. Many of them spoke of limitations associated with their disabilities. One respondent said, "As I told you before, my body does not respond because of the operation. It is like my body could not stand for a long time while performing a job. But even with the pain, with my disability I try to keep working in whatever is possible." Another respondent said, "I can not go to work. I can not walk fast, nor can I run. I can not be in contact with water for a long time because it affects me." Finally, the person who discussed his work in the community gave the following description of the limitations that his disability put on his activities:

> *Well, it is not the same freedom as someone who can move freely. People have to consider that many times I can not come to their homes. Or that many meetings can not be in a public place, the meetings have to be done here, where I live. It is not easy for everybody to say, "Let's work with him." . . . Instead they say, "I must go to his house." And that is a disadvantage. "OK, I have to work with him but it has to be in his house because he can not move." . . . In general, when they are needed they help. But one should be aware of how I am perceived by others and I should know that the fewer things I ask for, the happier people will be, or at least there will be less inconveniences for them. . . .*

Assistance of Family Members

The family members of the people with disability were asked about the type of assistance they gave to their relatives with disabilities. The answers that the family members gave ranged in length from one sentence to a lengthy paragraph, perhaps one measure of the extent of their involvement. Their comments were as follows:

> *If it was not for us, he would not live, because we do everything for him; he can not do anything, but he speaks and he did not lose his mind. . . . We ask people to do what he can not do. For example, he can not hold anything with his hands, nor can he hold a pen. We call someone to write for him. But around here, people have changed. In the past, people used to help. Not anymore, only if they get paid. And he pays too little since he does not earn much. He pays the people as soon as he gets paid. Thank God they have some pity for him, because he does not work [for a salary] . . . [but he] still receives some money. That is how he maintains himself; otherwise it is not possible. My daughter also works; that is how we help each other.*

> *It is because I am sick too. I am exhausted because I am old. She can not wash herself or brush her hair or get out of the bed by herself. Then sometimes I get weary.*

> *When he works on heavy tasks I apply pomades on him, herbs that warm him up. I apply them on his foot, where he has most of the pain. If he is cold then I apply the pomades or the herbs to warm up his foot. During the cold weather, his foot gets as cold as ice. . . . I also give him massages to warm him up.*

> *He said he helps his wife when she can not move by herself. He prepares the food and gives it to her. He also assists her during nights when she gets sick* (translator).

> *When he gets sick, we call the doctor to assist him. . . . I bathe him and I feed him. . . .*

Needs of People with Disabilities

People with Disabilities

All persons with disabilities were asked about their greatest needs. One respondent said that she did not have any needs because her family took care of her; this woman was the exception. Most of the respondents said that their greatest need was money. Each of them needed the money for different things; however, generally, respondents felt that if they had more money, their other needs could then be met. The following comments illustrate why money was so important to meeting their needs.

> *My greatest need is one such as, for example, 15 to 20 days ago when I went to Coatzacoalco to see the doctor. I spent [money] for two of us, because I can not travel by myself. . . . I can not get in or out of the bus by myself; it is impossible. The doctor told me that I have to go back. But I am not planning to do so because I do not have money. I went because my husband gave me half of the money and people helped me with the rest. I want to keep going since I have a daughter. This illness only keeps me suffering, but does not take my life away. It only makes me suffer. That is why I went. Two months ago I could not sleep at all. If I laid down then there was a deep pain; if I sat down, there was still pain. It was impossible; I could not do anything. At least now I can rest. However, I am not planning to go back because of the money. Where am I going to get the money from? That is my need. I have to see the doctor, but I can not go back anymore. . . . The medicine is not as expensive as the trip itself. You also need to eat something over*

there, but everything is so expensive. . . . My biggest need is to get a donation. I do not need the money for other things but for my health. Thank God that I have a family who works in the United States and have helped me a lot. They have helped me. In addition, the food is special, only fruits and vegetables. I can not eat meat. You know how expensive fruits and vegetables are. When you are healthy you can eat whatever you have.

My biggest worry or need is to have a job, to have an income so my child can study. Unfortunately, I did not have the opportunity to go to school and I have realized that it is very important. That is my worry, my first need. To have an income so my child can develop physically as well as mentally, otherwise they will be as poor as we are now. But if you help them they will succeed in many aspects such as economical, social, and for their family. That is my first need.

To be healthy and to work, just as I just told you. I do have many needs. Money is what is needed the most around here. If I do not have money, I can not go to the doctor or be under herbal treatment. Having money is my greatest need.

My biggest need is to have an assistant who is also aware of my people and that has the training. And I have the money to pay him and that we could do many projects. A trained assistant so I could ask him to do what I can not. Because I can not go to the forest, to the river, I only give indications, this should be done and . . . An assistant that could do many things.

Family Members of People with Disabilities

The family members of people with disabilities were asked their opinions as to the greatest needs of their relatives. For the most part, their comments were similar to their family members with disabilities. For example, the mother of the person who needed an assistant said, "To have someone to help him. . . . Money is what is needed, to pay someone." The wife of another person with a disability explained that her husband's needs were also primarily economical, not only for his immediate family, but for the extended family as well. She commented, "His father is now sick, he suffers from his feet too, and his mother does not work anymore. We should help them but what we have is very limited."

Needs of the Family Members

The family members of people with disabilities mentioned several issues when asked about their own needs. While the interviewed family members generally *first* referred to the person with a disability, or another family member such as a child or spouse (even when asked to address their own personal needs), it became clear in interviewing family members that they, too, had serious health concerns. As one family member commented:

> *Everybody has different health problems. . . . I have a lot of health problems related to my nervous system. It is in my head where I have more pain. I also use herbs and a liquor called aguardiente; I rub them on my whole body. Since my problem is of a nervous nature, I can not get upset; otherwise, I will faint. I also suffer from blood pressure and from gastritis. That is why I can not drink coffee, nor I can not eat spicy or fat food. I also suffer from colds. Everybody looks like they are not sick, but everybody suffers from something.*

One family member, who spoke through a Mixe translator, said that money to pay for medicine for her daughter was her greatest need. Another mother had a very similar comment when she said:

> *My biggest problem is food and the medicine for my child. He has been treated by a doctor but his bones have not gotten better. He does have a lot of pain. During cold weather, the child cries a lot and he has pain in his whole body, from head to feet. I have looked for a cure. Here, there is the herbal healing. But the herb we need can not be found here so someone sells it to us. That is how he is currently going to school, otherwise he can not go because of the pain he has. He is in pain when it is cold. When the weather is like now he even plays, but when it is cold he has to wear two or three sweaters and two or three pants. . . . It would be great if there were some help. There are many children around here that are growing up and who are sick, but they can not be treated because there is no money. What we earn is barely enough. However there are some who do have money. We work every day, but we do not earn enough.*

The husband of a woman with disability, who was assisted by a Mixe translator during the interview, said that he really needed some help in the fields, since his wife could not assist him either in the fields or in the home. The translator explained his answer in the following way, "A very urgent need he has, is to get help now that it is time to sow, to prepare the land. His problem consists of not having anybody to help in the field. His biggest worry is the work in the field because there is nobody to help him." Similarly, the mother of a person with a disability gave the following description regarding her need for money to pay an assistant:

> *I would like some help but I can not pay somebody to take care of him. We do not look for somebody to help him because we can not pay. I can not pay for them because I do not have money. I suffer from assisting him, giving him the attention he needs. For example, we can not move or sit him. I do not have the strength, neither does my husband. My daughter had an operation so she can not help anymore. The girls are in charge and are the ones who suffer the most. They are studying too. When I am too tired I go to bed and those poor girls help him get undressed, take off his shoes, or dress him. They help him because I am tired. Sometimes I help him when I feel well. I have high blood pressure. I can not lift him anymore. If I lift something heavy I lose my strength and then I need to go to bed to recover again. He is very heavy. It is easy to move him with two, but when there is nobody else the poor girls only push him to get him into bed.*

Effect on the Family

The family members had much to say regarding how the disability of the person in their family affected the family. One woman who lived alone with her daughter, who had a disability, spoke through a Mixe translator who said, "She said that it is difficult. Instead of her daughter helping her, she is the one who helps her daughter because she is not self-sufficient. She needs help because she can not move her arm; she can not move by herself." Another mother, although she was sad and seemingly exhausted from her personal assistant responsibilities, focused on the positive aspects of her son's character, rather than on his disability:

> *To the contrary, he is the one who helps his nephews since he is the one who studied. The kids help him, working or by doing everything*

> *that he says; he gives them advice. He tells them to study; he is the one who helps the family. Those nephews are the sons of his brother, who was constantly with him. He and his sister have helped him a lot. We are sad, we had so much hope in him. A misfortune what happened to him. . . . Yes, he is a role model for his nephews. Their father died and now they are orphans. He is the one who works. . . . He does his best working, from which we are maintained. There is nobody other than him. My husband is old and can not work anymore. My husband and I grow some [corn] as farm workers. He is the one who gives us advice, as well as to his nephews. The children in turn help him to go to bed, to get undressed. They help him in everything.*

The wife of a man with a disability talked about the fact that her husband's disability is hereditary and was passed on to one of their children. She explained in regard to her husband, "His muscles are not formed like ours are--they are different from ours. All his body is. It is the same with my child, my eight year old boy. He has the same problem as his father does."

With the assistance of a Mixe translator, one man talked about the resentment he felt because his wife was not able to help the family economically or through housework. The translator said, "He gets affected by his wife's illness because she can not help him in their marriage. For example, it is the wife who helps to solve a problem if the husband can not solve it anymore. But in their case, he has to do everything himself and he resents it. She can not take care of herself, then he has to do all the work."

Concern for the Future

People with Disabilities

Persons with disabilities were asked, "What is your greatest concern or fear for the future?" The following comments demonstrate that concerns ranged from money, to food, and to their children, particularly as regards access to education for their children.

> *That I have the economic resources to cover my expenses. By having economic resources I could have an assistant that could help me in my life. Economic resources that allow me to have the team to be able to work always, wherever I want, and precisely how I am doing right now--everything is right around me.*

> *My fear is how am I going to prosper if I get worse? How am I going to prosper if this illness keeps progressing?*

> *My biggest worry is (that) there will be some changes which I may not be capable of facing. In the past, we used to have a very different life in which to have an education was not necessary. Maybe that was because of a lack of communication or because we were not open to others, both to people from the community and from elsewhere. But at the present if you do not have an education, you will be condemned to misery. It worries me that I have limitations because of lack of education and I can not face the coming changes. It worries me that my children could be in the same situation I am in now. I think they should be prepared so they can solve the challenges they may be confronted with in the future. What also worries me a lot is my boy because I do not have money and his illness is progressing. What will*

happen to him in the future? That is very hard for me. It makes me very sad. My wife and I have really tried to look for options but we have only found dead ends. And it is like this because of our lack of education. That is the reason we are in a very difficult situation.

My biggest worry for the future is my daughter. My daughter, as I just told you about, she is eleven years old. When I started to be sick she was 15 months. Thank God she is older now and she can take care of herself. When she was in kindergarten it was so sad. She used to come back from kindergarten and wanted to eat. I was in bed and could not move. She started to cry then. She was hungry and I was hungry too because this illness makes you hungry. When you are sick you are usually not hungry, but not with this illness. My biggest worry is the girl. At least she can finish her primary school and if God wants her to continue . . . But who knows, now she is finishing primary school and she tells me she wants to continue. I tell here I can not say or do anything about it. I have tried and people have helped me. As I told you before, my husband does not have a job. That is why I tell my daughter I do not know if it will be possible. Her father has helped but he is also tired. He really has helped me a lot every time I get worse. He worries a lot. My biggest worry is my girl. My problem is to let her continue as she is now, because nowadays it is not enough to finish only the primary school. . . . I want my child to get an education, because there are some parents who do not even worry about it. They think that finishing primary school is enough. But how are they going to support themselves?

> *What worries her is that her nephew does his job in the field. That he grows corn and beans . . . What worries her is the money to help him. She needs the money so they can grow corn to eat. . . . She said her nephews ask her not to send someone to sow corn. They ask her not to worry about it. However she says no because if she ever wants to eat corn or a corn tamale where is she going to get it from* (translator).

Family Members of People with Disabilities

The family members of the people with disabilities were also asked about their greatest worry or preoccupation for the future. The comments below illustrate their concerns, again ranging from money for food, to money for education, to concern for the well-being of the person with disability.

> *I say to myself, "The day I die, he should die too." I would not like to leave him. That is what I think above all else. If I die who will be there for him. Death is the biggest fear. I wonder who will be there the day I die? How will they manage it? My daughter is tired too. She gets bored with assisting him. While I am still alive I talk to them and sometimes I grumble at them. I ask them to remember that he can not walk, that he can not sit by himself and that he lives through us. We had so much hope in him. We have always been poor and he had studied a career with which he was going to earn money. He lost it because of the accident.*

> *Getting money every day to eat is the hardest one. We wonder where are we going to get the money from? What will the children eat? And about the problem with my child in the future, I wonder. What would I do to attack that pain he feels so that tomorrow he will not suffer as he is now.*

> *He said his biggest worry is his daughter because she will finish the elementary school. He would like her to continue with junior high school, but he does not have money for that. Just as his wife said, money talks. What worries him is how are they going to succeed. He is a peasant; he does not earn enough money for that [junior high school]* (translator).

Responsibility to Help

People with Disabilities

The respondents with disabilities were asked who they felt was responsible for helping people with disabilities. Some of the respondents said that they felt the government was responsible for helping people with disabilities. For example, one respondent said, "I think the President, the one who is in Mexico City does." Another person said, "I could say that it is the government but I do not know if that is possible. . . . It is the president of the country. Because he is like a father. He is all responsible." Two of the respondents saw helping people with disabilities as a joint effort between the community and the government. Their comments are as follows:

> *I think it is a shared responsibility. In terms of medical instruments and equipment it is the government, as part of their responsibility of attending health issues. But if we leave it in the hands of the government, we already know how bureaucracy is to leave them with all the responsibility. Then it is a share responsibility, in which we also say what our needs are. To be solved based on our needs. Because usually, projects are not being made by people with disabilities, not by people who know what our needs are. I feel that it should be a shared responsibility and in this case health issues are very important. The*

government should help even more in these aspects and not rely on funds from other governments--from other countries--if they want to help us or not. Each of us should do our part, they as the government, we as a community and as a family, so it is a responsibility for all of us.

All of us. I think it is a responsibility of all of us. Of course, I know it is difficult since not all of us have the same attitude towards people with disabilities. We are used to receiving help from the government or from an institution. But sometimes there are other types of people, people of good will who can help us. I think all of us should have a good heart and help as much as possible the people with disabilities according to each situation.

Family Members of People with Disabilities

The family members of the people with disabilities also contributed ideas regarding who is responsible for helping people with disabilities. One family member commented, "Only the family. Someone else would not stand it. . . . In Mexico, there is no help to people with disabilities. If the person does not work, and the family does not work, how are we supposed to live?" Another family member said, "People from somewhere else, from far away" were the only ones who could/would help. The wife of a man with a disability said, "Only the doctors or people who know about herbal healing so they can help them." The husband of a woman with a disability reiterated, through a translator, the responsibility of the government. "He said he has an idea of who is in charge, the president of the country. But you need recommendations in order to see him, so it is better for him to stay here." Another family member said, "He who commands the Mexicans."

Recommendations

People with Disabilities

People with disabilities were asked to give recommendations regarding what could be done to continue documenting and advocating for the needs of persons with disabilities. The comments of those people who had recommendations are listed below.

> *My opinion is that there should be jobs so people with disabilities can work. As we already know, there are different types of disabilities, not everybody has the same disability. I think that according to the disability a person has, there should be an adequate job for each of them. For example, the engineer. Even though he can not move his arms and legs, he can perform another type of job. In order to survive, there should be a job according to the disabilities people have. . . . I only want to say that I hope this interview or the work that has been done, and will be done, would be heard. I hope it would be heard by the agencies or institutions to which this work will be presented. I hope we would be heard. I hope all the needs we have talked about could have a solution. I hope there would be altruistic people who would help us.*

> *It is state government who has the obligation to help people with disabilities. There should be jobs for everybody and not only for a few.*

> *A job has started but that information could finish only as information. Once a data base is available, then discuss it with the authorities, with the government, and if it is possible to receive help from foreign sources great, but it should not depend solely on it.*

> *Otherwise, the government gets us to receive help from foreign sources and it does not do its part. But if we do not suggest, if we do not contribute, then it will be a project that does not work, nobody will participate, nobody will do their part. And this does not help people to grow. In addition, if the project only depends on foreign sources or on the government, as soon as the help is over, the project is over too. That is why it is necessary to have a groundwork such as the research you are doing. But it is necessary that as a community we are aware that we have to contribute, and that we should not depend only on foreign sources or on the government to do everything. It would not work, it should not be like that. Or to utilize the resources that the government already has such as the clinic which pays its assistant. Let's utilize those existing resources that have been existing for a long time. Let's know how to use them in order for a project not to die. That is why the project of rehabilitation was oriented to the clinic. Because when there are already the staff and the space, then it is better to have there than somewhere else . . . Then we should take advantage of the existing resources and to present the project based on them so the project could last for a long time, not to create a new one that depends on external foreign sources or on the government. Then it is better to make strong what we have so it will continue.*

Family Members of People with Disabilities

Three of the family members had recommendations on how to continue the work with people with disabilities. One family member said, "Keep working because if you do not work how are you supposed to live." Another family member said, "Medicine, different types of medicines to help people." Finally, the third family member with a recommendation said, "Only by asking for help from the agencies so they can help with medicines. Only by doing so can something be done. Otherwise nobody will take responsibility for the people with needs because there is no money."

DISCUSSION

A total of 64 people with disabilities from the Mixe district responded to the survey. The vast majority of these people were originally from the town of Totontepec; however, two were born in neighboring towns. All of the respondents reported that their ethnicity was Mixe. The majority of the respondents (83%) said that their first language was Mixe. In terms of gender, 58% of the respondents were female, with males making up 42% of the population. The majority of the respondents were adults. The data demonstrate that among all respondents, poor vision, arthritis, "muscular dystrophy" (any type of muscle weakness; any type of muscular degeneration), blindness, and deafness were the most common disabilities. The quantitative results indicate that the greatest needs among the 64 respondents were medical attention, family support, physical rehabilitation, and health care. Data from the ethnographic interviews indicate that proper medical attention, physical rehabilitation, and health are very difficult to obtain unless the person with a disability has access to money.

The results regarding the need for medical attention, physical rehabilitation, and health care among the people with disabilities in Totontepec are particularly alarming when one considers that 95% of the survey respondents reported that they did not have access to disability-related services. Even though there was a medical clinic in Totontepec with newly installed physical therapy equipment, the survey respondents did not consider it a rehabilitation center. This is reflected in some of the comments that were made by the six people with disabilities who responded to the ethnographic interview. As was reported previously, they felt that the clinic was for conditions such as broken bones and childbirth. One man said, "There are other types of services such as medicine, for people who need medical assistance of another type. But specifically for people with disabilities, there is nothing." Often, people with disabilities need specialized attention that the local medical clinic does not offer. For example, one woman, who had a congenital disability, reported on the quantitative survey that she needed medical attention and then made the following comment to the interviewer, "Specialized medical attention because the doctors at the clinic do not know how to care for me." In addition, consider the description of having to travel to Coatzacoalco to see a special doctor that was given by one of the women who responded to the ethnographic interview. Unfortunately, she did not have the money to continue traveling to Coatzacoalco in order to benefit from the specialized attention.

Perhaps the lack of specialized medical attention helps to explain the need that many of the survey respondents had for family support. Following medical attention, family support was the most commonly reported need among all of the sub-groups. For example, 49% of adults, 64% of children, 50% of women, and 48% of men reported that they needed family support. Unfortunately, the qualitative data reveal that this need for constant care by the family can cause a lot of family stress. Consider the man who said that he resented the fact that his wife was not able to help with anything due to her disability. Another example is the mother who said that when she died, her son should die also because other members of the family were either not able or were tired of taking care of him.

Even though a relatively low percentage of the survey respondents said that they needed physical rehabilitation, it was the third most commonly mentioned need. Only 26% of adults, 27% of women, and 26% of men cited physical rehabilitation as one of their greatest needs. However, 55% of the children reported that they were in need of physical rehabilitation. The comments of one of the people who responded to the ethnographic interview indicate that physical rehabilitation may soon be available to people with disabilities in Totontepec. This person's comment was, "Just recently, rehabilitation equipment was brought in but it is not working yet. It is brand new and the nurse is being trained."

One possible reason that the need for medical attention was so much greater than the need for physical rehabilitation may have been that the majority of the reported disabilities were not physically manifested. For example, disabilities such as poor vision, blindness, deafness, epilepsy, developmental disabilities, and autism represented almost three-quarters [74% (47)] of the disabilities that were reported. Each of these disabilities require specialized attention that is not available at the local medical clinic in Totontepec. Examples of specialized services that would meet the needs of the survey respondents are optometry, otology, special education, and vocational rehabilitation.

Six (55%) of the children who responded to the survey were old enough to attend school. Each of these children reported that education was one of their greatest needs. This was not the case for the adults, 15% of whom reported that education was one of their greatest needs. However, some of the comments of the six adults with disabilities who participated in the ethnographic interview described the importance of an education. Consider the man who said, "But at the present if you do not have an education, you will be condemned to misery. It worries me that I have limitations because of lack of education and I can not face the coming changes." In addition, this man and other respondents who had children, said that they hoped that their children would be able to get an education. One woman said, "My biggest worry is my girl. My problem is to let her continue as she is [in school], because nowadays it is not enough to only finish primary school."

One of the greatest needs revealed through the ethnographic interviews was money. The respondents indicated that if they had more money then their other needs could be met. Some of these other needs were medicine, medical care, education for their children, and personal assistants. Each of these respondents indicated that they wanted to work and that they had worked in the past but they were now unable to find work in Totontepec due to their disabilities. The inability to find work was also true for the majority of the adults who responded to the quantitative survey. For example, nearly three-quarters of the adult respondents [74% (39)] reported that they did not have an income.

Given that there were very few work opportunities for people with disabilities in Totontepec, some participants in the ethnographic interviews suggested that the federal government, state government, president, or community were responsible for assisting people with disabilities. However, two respondents said that they felt the needs of people with disabilities were a joint responsibility between the government and people with disabilities. Ultimately, no matter who has the responsibility to assist people with disabilities, the data from both the quantitative survey and the ethnographic interviews demonstrate that life is very difficult for people with disabilities and their family members in Totontepec. The data show that most people with disabilities in Totontepec depended on family members for their living expenses and for their personal care. Even those people with disabilities who had jobs reported that they did not earn enough to meet their own living expenses.

Research Process and Dynamics

The results of this study confirm that a methodology which is guided by the tenets of Participatory Action Research (PAR) is the most effective strategy for assessing the needs of indigenous people with disabilities in rural, remote areas. Some of the important factors that lead to the success of a PAR strategy are wide spread local support, face-to-face interviews conducted by local people with disabilities, and returning the data collected from the community to the community in a usable format. Through this research project, as well as the *Vecinos: Phase I* (Marshall, Gotto, Peréz Cruz, Flores Rey & García Juárez, 1996) and *Vecinos: Phase II* (Marshall, Gotto, Galicia García, 1998) projects, AIRRTC researchers have developed research procedures that can lead to useful research results that will directly benefit the participating community. These procedures are summarized below:

1) Hire an on-site research coordinator from the participating community who identifies culturally with the respondents and who understands and is committed to the tenets of PAR.
2) Create widespread community support for the research project through the development of a Project Advisory Committee (PAC).
3) Involve the on-site research coordinator and the PAC members in the development of a culturally-appropriate survey instrument.
4) Conduct interviewer training with local people who identify culturally with the survey respondents.

5) Once the data are collected and analyzed, hold a meeting with the PAC in order to discuss the results, their significance to the community, and future actions to be taken based on the results.

6) Hold a community meeting or public forum to disseminate the initial results and solicit ideas for future action.

7) Write a Final Report with the on-site research coordinator which will be disseminated within and beyond the participating community.

CONCLUSIONS

One of the main purposes of the *Vecinos y Rehabilitation* projects, including Phase I and Phase II, has been to establish the feasibility of conducting major research and training projects involving indigenous people with disabilities in Mexico. The *Vecinos y Rehabilitation* projects have been conducted in progressively more rural and remote locations with each new phase. Phase I research was carried out in Oaxaca City, a relatively large city and the capital of the state of Oaxaca, along with two rural areas in the mountains and on the coast. Phase II of the research was conducted in the rural areas of the Mixteca region of Oaxaca, but the base of operation was in the small city of Huajuapan de León. Finally, Phase III has been carried out in the Mixe District in the very remote and rural town of Totontepec.

Conducting an international research project, which seeks to include local people in the research process, can be an arduous and stressful task. This is particularly true of a project that involves the participation of people from varying education levels, various cultural groups, separate countries, and different language groups. Additional barriers are created as a project moves to remote, and rural areas. For example, during Phase I of the research (in Oaxaca City) AIRRTC researchers were able to call the on-site research coordinators directly, send faxes, and send and receive packages via Federal Express. In contrast, AIRRTC researchers were not able to make a direct call to the on-site research coordinator in Totontepec because there is only one community telephone in the town. Therefore, the protocol for talking to the on-site research coordinator was to call the community telephone center, tell the operator with whom one needed to speak, and then call back in 20 minutes after the person had been notified that he/she would be receiving a call. In addition, there were no fax machines, no e-mail, and no overnight delivery services in Totontepec.

The barriers to international research in remote, rural areas would seemingly indicate that major research and training projects are not feasible unless the researcher has a lot of time, or is willing to live in the community where the research is conducted. However, AIRRTC researchers have found that a research methodology which is based on Participatory Action Research (PAR) is quite feasible in terms of money, time, and work effort. In other words, a project that includes local, indigenous people in every step of the research process, from inception to dissemination, is quite feasible. Because of the barriers that exist, a research methodology that is based on PAR is particularly important in rural, remote areas--especially when it is considered that the needs of indigenous people who live in these areas have never been chronicled and that disability-related services very often are not available.

A second purpose of the *Vecinos y Rehabilitation* projects has been to develop a program of information exchange in Mexico involving experts in the field of rehabilitation and Native peoples. During each phase of the *Vecinos y Rehabilitation* project, a concerted effort has been made to bring indigenous people with disabilities from Mexico to the United States as well as to bring rehabilitation experts from the United States to Mexico in order to develop an information exchange. As was mentioned previously, Mr. Bernal Alcántara, the Phase III on-site research coordinator, traveled to the United States where he had the opportunity to talk with and share ideas with rehabilitation professionals and American Indians with disabilities. In addition, Ms. Ela Yazzie-King, a Navajo woman with a disability and the Regional Coordinator for the Indian Children's Program on the Navajo reservation, traveled to Totontepec. At the community meeting in Totontepec (see Appendix F), Ms. Yazzie-King gave a presentation about the services that are available to American Indians with disabilities in the United States and spoke of her own experiences of growing up on the Navajo reservation with a disability. In reflecting on her experience in Totontepec, Ms. Yazzie-King concluded that, "The indigenous people of Oaxaca frequently demonstrate self-reliance in the face of minimal fiscal resources. American Indians need to re-learn self-reliance, a quality lost after years of dependence on Federal government programs which often turn out to be short-term."

Ultimately, it is hoped that the exchange of information and knowledge that has occurred as a result of the *Vecinos y Rehabilitation* project will help to shape culturally-appropriate and cost-effective rehabilitation programs that serve indigenous people with disabilities in both Mexico and the United States. Similarly, it is hoped that the information gained through this study will help to inform policy makers, both in the United States and Mexico, that rehabilitation intervention must accommodate the cultural needs of indigenous people with disabilities.

RECOMMENDATIONS

Research Process/Future Research

Working as a bi-national and multicultural research team has taught the members of the *Vecinos y Rehabilitation* research team many lessons about how to successfully complete an international applied research project with limited funds and time--specifically, applied research in rural, remote areas. Recommendations for completing any future research in a timely manner include:

1) Only conduct research in areas where you have established contacts and/or have been invited.
2) Create a sequential work plan that includes completion dates for each activity and strictly adhere to these dates in order to insure the timely completion of the project.
3) Involve community members in the project as much as possible in order to give them ownership of the project and its results, and in order to cut down on the travel costs of the academic researchers.
4) Conduct a thorough interviewer training with qualified community members who would like to serve as project interviewers in order to insure the quality of the data.
5) Conduct a thorough training on data entry and analysis with qualified community members.
6) Pilot-test the survey instrument to make sure that it is appropriate and to identify any flaws in the instrument.
7) Have copies of the survey available in relevant languages that are spoken by the survey respondents.
8) A study needs to be undertaken on the types of assistive technology indigenous people in rural areas have developed (devices as simple as

using a rubber band to hold a spoon) in order to document and share these devices with other persons who have disabilities, but minimal fiscal resources.

9) A study needs to be undertaken documenting the plants and herbs that the Mixe use to alleviate health-related problems associated with disabilities (such as in the case of spinal cord injuries, the prevention of kidney problems is believed to be achieved through use of the plant *Guia de chayote* [Sechium edule L.]).

The Town of Totontepec

The research results led the members of the research team to consider the implications of our findings for the people who participated in this research process. This reflection led us to the following recommendations:

1) Continue to develop education opportunities for people with disabilities in Totontepec, children in particular.
2) Seek employment opportunities for people with disabilities in Totontepec.
3) Create a support group for people with disabilities where they can talk about their needs and problems, and work together to find sources of assistance and solutions to their needs.
4) Create a support group for the family members of people with disabilities.
5) Aggressively seek opportunities to bring specialized medical doctors to Totontepec at least once a month to serve those people who need specialized medical attention.
6) Remember that family support is tremendously important, for example, when personal assistance care is needed. However, family support needs to be balanced with respite for the family members

providing care. Family members providing substantial amounts of support should be given opportunities for their own learning and self-growth, both in areas of work as well as avocation.

7) A two-pronged respite program to provide (a) support to the family and (b) personal assistance to persons with disabilities should be developed. Such a respite program would not only provide relief and support to exhausted family members providing care, but also needed employment for the person who is providing respite.

8) Develop a paraprofessional in-home outreach program such as the *Treatment extender* program developed at Sage Memorial Hospital in Ganado, Arizona. In such a program, a rehabilitation or medical professional would design the treatment plan/rehabilitation program, but the *treatment extender* (the paraprofessional) would be available to meet with the family frequently, for example, on a weekly basis and would work with the family for an extended period each visit, for example, two hours. The treatment extender should be a person from the Mixe community who speaks the Native language and who would be trained in understanding and working with families, as well as persons with disabilities.

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Appendix A

The Mixe

Juan Arelí Bernal Alcántara

THE MIXE

Juan Areli Bernal Alcantara

Translated by: Leticia Green

Edited by: George S. Gotto, IV, M.A. and Catherine Marshall, Ph.D.

Juan Areli Bernal Alcantara is the Director of the Instituto Comunitario Mixe, Kong Oy *[Mixe Community Institute, Kong Oy], located in Santa María Totontepec, Mixe, in the state of Oaxaca, Mexico. Mr. Bernal Alcantara has quadraplegia and participated in the AIRRTC community forum held in Oaxaca City on December 2-3, 1995. This forum was held in order to present the results of research (Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996) conducted in Oaxaca as a result of a supplemental grant awarded to the AIRRTC by the National Institute on Disability and Rehabilitation Research (NIDRR). NIDRR has maintained an international research program for the past several decades*

(see accompanying summaries reprinted from recent NIDRR publications).

Location

The Mixe are the people that call themselves the *Ayuuk Jaa'y*, which means "People of the Mountain." This ethnic group covers 19 counties; 17 of which combine to make up the Mixe District. This is the only district on a national level that is named for a specific ethnic group. The Mixe have 150 villages. The population of the Mixe is approximately 150,000 habitants.

The Mixe territory covers 1,802 square miles, located in the northeast section of the state of Oaxaca, within the hills of the Zempoaltépetl mountain. This mountain is 11,142 feet high. The territory is divided into three zones: the high zone, its altitude reaches more than 5,906 feet above sea level; the middle zone, which is at an altitude between 4,265 to 5,906 feet above sea level; and the low zone, which includes anything below 4,265 feet above sea level.

Origins

There are three theories related to the origins of the Mixe. The first links the Mixe to Peru, the second theory refers to European descent, and the third connects them to the Olmecs. The last theory is the most congruent because of the close geographic, linguistic and physical characteristics of the people, and the oral histories that exist in these regions.

Means of Subsistence

The majority of the villages are dedicated to agriculture. For example, they grow corn, beans and squash, using two systems: they plough the land using animals in a yoke and they use the slash and burn method of cleaning of the land. In the center of the Mixe District they grow coffee, and on the lower areas where the land is most productive, they raise cattle on a large scale. In the majority of the villages, they raise chickens and cattle in small scale. They use animals to transport their wares because there are no roads leading to many of the villages and the terrain is very steep.

In some of the villages they still make handcrafts, pottery and clothing in small quantities. Commerce is another avenue to income in which products from the city are sold. Every town holds their own market one day each week when individuals sell or exchange products.

Social Organization

The organization of every Mixe town is based in the authority of the civil, religious and other organizations. The two most important authorities are the municipal authority and the religious authority. The religious authority does not mean clergy, but represents the members of the community. Also, there are authorities for music and education, but all are under the municipal authority. The structure of the communal organization gives strength to the villages and to the individual and provides the element for active participation within the *tequio*, which can be described as community work performed gratis for the benefit of the community, as well as the accomplishment of civic responsibilities, without a salary. The life of the Mixe is completely oriented in the community. The elderly are very respected and they are very important in all decision making. They come together as either an Elder Board or Meeting of the Principals.

The family holds a very important role in their social organization. The father is the authority that coordinates all the activities including the organization of their land and the religious festivals. The women are submissive and passive and they dedicate the majority of their time to attending their home, but they can also participate by working on the fields to help their husbands and sons.

Continued on page 10

The more the women participate in agricultural activities, the more they participate in vices such as the consumption of alcohol and tobacco. Other ways in which women contribute economically are through their employment as teachers or bureaucrats; they also have the income from their daughters and sons that have migrated to big cities such as Oaxaca City, Mexico City and in some cases to the United States.

Religion

Officially, Catholicism is the most predominant religion in most of the villages. This is manifested during two of their patrons celebrations, one dedicated to the Patron Saint and the other to the Virgin Mary. Recently, the Mixe have been approached by some Protestant sects that have led to divisions within the villages and the disappearance of some customs and traditions.

The combination of differing beliefs, syncretism, exists in worship. For example, in some of the villages you will find that in the Catholic church at the altar, or behind the church, are the stone statues of the Mixe gods, they are hidden so that the priests will not discover them.

The Mixe have their own divinities which are represented in the mountain named Zempoaltépetl, Mountain with Twenty Points or Twenty Gods; and, they sacrifice small animals to them (e.g., roosters and turkeys). They also offer food such as tamales and tortillas, votive candles, and alcoholic beverages such as mescal. These offerings are given in conjunction with their request for generous crops and good health for their families and their communities. The Mixe also believe that the king, *Kong Oy*, still lives in the mountain. This king is the symbol of liberty for the Mixe, since they were never defeated by the Zapotecs, and the tradition reveals that the king did not die but he entered a cave in the Zempoaltépetl and still lives there. Generally, each village has their own ceremonial place for sacrifices, and in their own manner.

Values of the Mixe

The Mixe vision of the cosmos permits them to be a cohesive group, based in a common language (Ayuuk), common land, ancestral religion based on the Zempoaltépetl mountain, and their respect for nature. Another element that should be considered is spirit of alliance based on the king, *Kong Oy*. The Mixe community structure is the core value; everything revolves around the community. For that reason, individuals contribute to the community through the tequio, helping neighbors to build their houses and to take care of their land and crops. Festivities and Funerals also play an important role in the integration of the community. Mixes retain prehispanic traditions like respect for nature and for life. The art of music has been developed and there are organized music bands; they play their own music and are recognized within the state and around the nation. Another very important value the Mixe have is the simplicity of the people which allows them to have a quality life without the accumulation of wealth, but rather service to the community. Everyone provides service to the community and everyone accepts assistance, resulting in a free exchange of community service and community assistance.

Cultural and Social Problems

The most important problem for the Mixe is the ownership of the land, because many of the villages do not have clearly-defined land ownership documents, or because there are not definite boundaries. This problem is the consequence of counties that shared property and never established their borders. Another problem is the extreme poverty. The land on which the Mixe live is not very productive because it is on steep hills, and the layer of good soil is very thin. There are no paved public roads. Another major problem is health, there is a very high mortality rate among the children due to poor nutrition, which affects education which, in turn, adds to the economic problems. There is also a lack of schools.

A cultural problem is reflected in the disappearance of many of Mixe traditions and prehispanic customs due to the influence of massive communication systems such as radio, television, and the movies. The nationalistic education has also influenced the disappearance of the Mixe language. In addition, this education is outside the social and cultural beliefs of the Mixe and the results are seen in deculturization and the immigration to, principally, Oaxaca City and Mexico City. This immigration has an influence more negative than positive, because when people return to their own villages, they only bring bad habits and vices.

The Mixe clothing that is made by hand is disappearing due to the influence of the big cities, and because of the lack of cultural identity consciousness. This attire is made by hand on a loom tied at the waist and it is very elaborate. The pottery is also disappearing due to the introduction of plastics and metal.

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Appendix B

Letter from
Juan Arelí Bernal Alcántara

Totontepec Villa de Morelos Mixe Oaxaca, a 1 de Junio de 1996.

Catherine Marshall
4043 Alhambra P1
Tucson A Z 85711

¡ Hola Catherine!:

Te mando un saludo desde estas montañas del noreste del estado de Oaxaca, esperando que estes muy bien.

Deseo agradecerte infinitamente tu invitación y viaje a Arizona. Fue un viaje muy importante y agradable por todo lo que aprendí y lo que me hicieron sentir, muchas gracias por tu confianza depositada en nosotros, pero sobre todo tu amistad. Esta experiencia nos ayudará mucho en nuestro proyecto y me obliga a pensar más en mis hermanos con limitaciones físicas.

Creo que te voy a tratar de imitar en tu sistema de comunicación por computadoras, tratando de pagar a crédito la computadora que necesito, a la cual trataré de hablarle y que haga las cosas solo, sugún me informaron en Flagstaff.

Ojalá nos visites pronto otra vez , que nos dará mucho gusto, para que convivamos más tiempo.

Con mucho afecto.

Juan Arelí Bernal Alcántara

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Appendix C

First Congress Regarding Disability in the Mixteca

Huajuapan de León, Oaxaca
August 5, 1996
Juan Arelí Bernal Alcántara

First Congress Regarding Disability in the Mixteca

Juan Arelí Bernal Alcántara

Transcriber and translator: Joyce Y. García

A very good afternoon to you all. I want to thank Ovaldo and all the organizers of this important event in a very special way for inviting me. I was very pleased to be invited. My subject is going to be a little different from what has already been presented . . . You know that I'm from the Totontepec region, which is northeast in the State of Oaxaca. This [region] has 19 different municipalities and it's just the ethnic groups that are more resistant to change in the sense that they preserve many of their traditions. . . . The importance of our culture, our integrity, made me reflect more on the aspect of persons with disabilities . . . and the context we give it in our Native groups. It seemed that there was no . . . way to designate persons with disabilities [in our Native language].

Also important to me is we must think about our surroundings, our environment, where we live. We have to . . . and not always be thinking about our city or in the larger sense, the nation or abroad. Why? Because when we don't value what we have, when we aren't aware of how important we are as people, as an organization in our own area where we live, we aren't going to be able to gain much. Why? Because there is no identity to help the group. We'll always be striving to be what we're not and what we want to be and we don't accept what we really are. So in that sense, it is also important for us to reflect on the fact that each community, each group, has the values that are really important for them as human beings, above all, as a group. . . .

For example, the Mixteco group is very important in the culture of the people of Oaxaca. It's a very important story. . . .

My thought is that we shouldn't try to . . . see what is bigger. . . . Rather, we should try to make things better in our own environment. Let's face who we are as a person. How will we be better persons? By serving more. The more we serve our neighbor, the more important we'll become. That's one of our values among indigenous peoples. We always speak in plural; we almost never speak in singular. It's our town; it's our party; it's lots of things that are ours. The indigenous groups have a lot to offer in that regard. . . .

More specifically, we, the Mixes, have three classifications of conditions of health which you can see there [referring to poster]. One is strong and healthy. It's the person who can walk without any problems; the person who can do everything--who has no physical limitations. That's the first aspect. But that's an individual aspect. In a collective sense, it's the well-being that we say that a person is well and healthy-looking, but more than healthy-looking, is in harmony with others. . . . That means that a person is doing well in society, that society views the person in a good light. . . . Whenever a person is no longer "good-looking," not to themselves, but in society, then that person can start to have health problems, that is a psychic or mental problem. Then it begins to affect the person. For example, when a person isn't accepted by society, they begin to get sick. So well-being is related to being strong, healthy, well, and good-looking. In Mixe, we say *mok* for strong, *tsotz* for healthy, *oy* for well, and *oy akxon* for well-being from the standpoint of society. So the first aspect [of health] would be to be well.

The second aspect is a physical limitation which we call *ma'at*. . . . What it really means is a physical limitation. The literal translation would be "broken," but what it means is limitation. That it's more difficult, that the person is slower, etcetera. But the person isn't sick. Am I making it clear? The person isn't sick physiologically. The person isn't sick. It could be that the person has problems with a leg, with an arm, whatever, but the person isn't sick physiologically. . . .

The other important aspect is those who are sick. That's the third category. In that regard, it's whoever is sick, confined to a bed--someone who is physiologically sick and confined to bed. And in that sense too, whoever is *ma'at,* that is, a person who is broken, who can't be rehabilitated, who has no guidance, who doesn't understand about wheelchair equipment and who is bedridden. We also call that person sick. . . . If someone doesn't have any guidance, has no equipment and is thereby confined to bed, that's a sick person. They are "broken" in the physical sense, but for economic reasons, or lack of awareness, they are also a "sick" person. Perhaps that's the most important theme that concerns us so that we can do something about it. If we already saw and understood the three categories of health we have--the person who is fine in relation to herself and her environment; the one who has physical limitations; and the one who is sick, either because she doesn't have the means to walk or because she is really physiologically sick--fine, then let's see, what do we think health is? What do we understand good health to be?

We understand health in this way: first to eat, to eat and drink food in agreement with its natural state of cold or hot. . . . You know that it is said, this is cold and if you combine cold with hot, it can be bad for you. So it should agree in such a way that what you eat won't be bad for you. . . . Another important condition that we have for good health is to be in harmony with nature, with our surroundings. If I didn't, or we didn't, make a sacrifice, some act of appreciation toward nature, some kind of dialog with nature, that could affect our health. A simple example. If for example, I go to the fields to work, I fall down and I get mad and swear there, I mean I get mad, then I know that I'm going to be sick the next day. It's not a psychological illness. You get sick. So then the cure . . . you have to go ask the earth or wherever it was to forgive you. You take some dirt and tie it to your leg or wherever it hurts and then you get well. So then that's why it's important to be in harmony with nature. Also because the Mixe farmer, since she depends so on the earth, that's her foundation, her food. So you have to have a good relationship. So when you take, you have to give to the earth. When you eat in a special way, you have to give to the earth too. So you talk to the mountain, the rock, the earth, the water, all of which are life giving forms. It's always that relationship that humans have with their environment and so forth.

Another form [of health] is to fulfill all the responsibilities with the municipal authorities, that is, with society; you have to be right with society. Because if I don't do something that the authority indicates to me, and I had accepted it, I can get sick from that also. That is, I can attribute it to that since I didn't do what I was supposed to as a member of a society; I can get sick. So you have to be right with that too. And you have to meet those responsibilities that you've set out for yourself. All the things you promise to do, you have to fulfill because otherwise you can also get sick. We also think that our relationship with our ancestors is very important--we have to be right with our ancestors, those who have already died. We have to make celebrations among the saints . . . so we can be in harmony with them too so that we'll have good health as a result. If I don't meet my responsibilities with my grandparents, they can get angry and come and make me sick. Those are the aspects we have in order to be well, to be healthy, because otherwise we can have the problem of getting sick--because of not eating right, or because we're not in harmony with nature, with the authorities, with society, in the religious sense, and with our ancestors.

There's also the aspect of how we recuperate from bad health. We have to be in harmony. When someone is sick, first we try traditional medicine. First we use herbs; first we try everything we have at hand at home. When this doesn't work, then we go to the clinic, to some small clinic or a medical dispensary and if we don't get cured with that, then we go to the seer, the one who divines things by the sun. It isn't really a witch doctor; it's really a person who keeps the Mixe calendar. There are parallels, there are appropriate times to do something in benefit of the family, of health, whatever it might be. We go to see him and he guides us as to what to do to regain our health. What's more important to us in that sense is, for example, as we were saying a while ago, that you might have physical limitations and you don't have the means, or the guidance; without professional guidance and the knowledge, unfortunately, you're considered sick. It's also a disadvantage. You may notice that if our families, [if] we ourselves don't know how to handle our problem, it's most likely that we'll be laid up in bed practically waiting just to die. . . .

The speech the woman gave about her experience was very important; the experience of the wife, the daughter, because these are workshops where we are allowed to offer security to the family--to the person. When we hear them, they help us learn how they've solved their problem and the problems still to be resolved. It's very important we, sadly over in the [Mixe] region . . . we don't have a vocational center to offer guidance for rehabilitation. Those concepts don't exist due to lack of knowledge; these things don't get treated.

For example, if in my case, with the accident that I had, if I hadn't been in the city, or didn't have friends, then surely I would be in bed in my town, sick--a sick person. But thanks be to God, with friends, with everyone, I had guidance, and here we are in dialog and thank you for the opportunity. That's what I wanted to say to you, that this is the way in which we see health. . . .

Another aspect which is also essential--when we see things from the point of view of our environment, we can find many solutions to problems of disability. For example, when I returned to my town, my legs were really stiff and it was really difficult to move. Do you know how I solved it? I went to *temascal*. I don't know if you still have the tradition of *temascal* here. But if someone has a contracture, that is, if someone suffers contracture, they can get in the *temascal* two, three, four times and the contracture goes away immediately. So if a person with contracture treats themselves with *temascal*, they'll get relief.

There are some herbs, for example. I've been in a wheelchair for 17 years and, thanks be to God, I don't have any kidney problems--no stones, no infections and that's entirely due to the herbs. As you can see, if we think about what we have at hand, it can really serve us well. Because otherwise we'd always be thinking about antibiotics, about operations for gallstones. We'd always be relying on that state of mind, parochialism which we said is also important because they have made advances, but they also have greater problems than we do. For example, the United States is a very advanced people. Yes, but they've gotten themselves into wars all over the place and that's why they have more people in wheelchairs.

I mean, there have to be problems, of course, but they're organized and have solved problems more quickly and have advanced more. But like we were saying, we can solve some problems in our own environment, without ignoring knowledge that comes from the outside; because, for us to be radical wouldn't be good either. How can I say it? To learn only what we have here and everything else is bad. That's not a good attitude either. Because we become radical if we go to extremes and we don't learn to live together. We have to learn how to get along with other cultures--not that my Mixe culture is more important than the Mixteca or Zapoteca culture or the city is more important; they're all important. They are important. So then there's respect. Therefore, we have to learn to live together so that we can help each other. That's why organizations are very important; yes, we have to get organized.

Another very important aspect is education. If we don't want to get an education, if we don't try to get an education, it will be very difficult or more difficult for us to grow; life will be more difficult. So I really encourage you to study whether it's getting training for work or by formal studies. Maybe I speak so confidently here is because I already have a career. I thank God that I finished my studies for my career in spite of my accident and because I also wanted to make it. . . .

And something else that has helped me a lot is the workshops. Like I was saying, in December of last year I really hadn't had time to see my problem of having a disability. I haven't had time. I have so many things to do that I hadn't seen it. So I began to think when Germán and Pedro invited me to come say a few words [in Oaxaca City]. I said, what should I talk about? Well sure, because I don't have the experience of so much rehabilitation, because my mind is so occupied with other things, not as an escape but because my objective was to serve my people. That was always my objective. So thanks be to God, I was able to go back [home] and we're doing something there. So I didn't have time, but with these workshops, with these meetings and with the trip to the U.S., I said okay, I also have to try to help my neighbors who have disabilities. Otherwise I'm involved in so many things over in my community that I didn't have time. So then I thought, we have this possibility of getting to know this area, feel it, venture out, however it turns out. Thanks be to God, to the family, above all friends because I can't talk with such confidence if I don't have the support of family and friend and God.

So, in that regard, I encourage you to always try to continue to study and to learn. Education is so important and that's how we can do projects for ourselves. We can think and write about what we want for our benefit and all society. We can strike up relationships with people who are far away through letter writing. That can be very useful. But if we don't learn by getting an education so that we can share our experiences, it will be very difficult to make it. Let's not close ourselves off, let's do get to know each other, the more we can do for ourselves, for our environment, and be able to make it in that way. This is what I had to share. If there are any questions, please do ask and I'll be glad to answer.

Appendix D

Survey Instrument
and
Interview Protocol

CENTRO DE INVESTIGACION Y ENTRENAMIENTO
DE LA REHABILITACION DEL INDIGENA AMERICANO

Totontepec Villa de Morelos

Instrucciones: Señale solo una respuesta para cada pregunta.

DEMOGRAFÍA

1a. Nombre/tii mxëëj ____________________

1b. Apellido/ti mmutö'k kuya'ax (1) ____________________

1c. Apellido/ti mmumäjsk kuya'ax (2) ____________________

2. Localización/jöma tso mtsüüna

____

____

____

3. Teléfono/juu' mtelëfono ____________

4. Sexo
☐ Masculino/yaa'tyëjk
☐ Femenino/të'ëxtëjk

5. Fecha de Nacimiento/ti po'o, ti matsyo'bën jats ti jöönt mge'x

___/___/___
M D A (o aproximado)

5a. Años Cumplidos/binxüp jööndans mitse'e pu'uk _____

6. Estado Civil/yaa'byük mitse'e? të'ëxpük mitse'ë

- ☐ Soltero (a)/naaydum
- ☐ Casado (a)/nabyükjü
- ☐ Viudo (a)/ kuëë'k
- ☐ Divorciado (a)/namyaasë'ëkjü tsuunyip
- ☐ Otro/biijnk

____
(¿Cual?/juu')

7. Escolaridad: Grado último de estudios/ jöma baat tse'e m'ixpüjk

- ☐ Sin Educación/ka'a y'ixpüka
- ☐ Primaria/mutö'k ixpëjkün
- ☐ Secundaria/numäjtsk ixpëjkün
- ☐ Preparatoria/mutööjk ixpëjkün
- ☐ Profesional/mëjü ixpëjkün

Especificar su profesión/tii nü'ixpëka mjayejpp

____

8. Ingresos Económicos/mmeembëjkp mitse'e
☐ Sí/be'em ☐ No/ka'a

8a. ¿De donde vienen los ingresos económicos?/bindso meen xpaa'ty?

- ☐ Empleo/mdöömp
- ☐ Pensión/mdön'atübinu jats jä'ä myaktukn
- ☐ Otro/biijnk

____
(¿Cual?/juu')

8b. ¿Si está empleado, cual es su ocupación?/ pën mdöömp jti tse'e mduump?

____

8c. El empleo que tiene es/bin'it mdun:

☐ Temporal/to'majaty

☐ Permanente/ijtp

8d. Si es permanente, ¿recibe los beneficios que por ley se corresponden?/mpüjkp tse'e ju'u am jo'n kutuk y'it

☐ Sí/be'em ☐ No/ka'a

8e. ¿Usted esta de acuerdo con el trato que recibe en su trabajo?/m'oyja'bipe'e bindso jä mbindsën jats jä mm'atööjnk jyayubada mëët mits

☐ Sí/be'em ☐ No/ka'a

8f. ¿Con el sueldo que gana satisface sus necesidades, por ejemplo, alementación, vestido, casa?/mnüpaadixjp tse'e oy jä mjö'yüm

☐ Sí /be'em ☐ No/ka'a

8g. ¿El sueldo es suficiente para satisfacer las necesidades que tiene en relación su discapacidad?/mnüpaadixjyo tse'e oy ja mjöyön ax jön mitse'e mganatyök tsotsa

☐ Sí /be'em ☐ No/ka'a

8h. ¿Como ha hecho para relacionar su discapacidad con su actividad en el trabajo?/bindso tse'e xjatun jatse'e mdööng

____

____

____

9. ¿De qué pueblo es?/jöma tse'e mkukajpüna

____

____

10. ¿Qué idiomas habla?/juu' jaty dyöök tse'e mkëjtsp

☐ Mixe/ayuöök

☐ Zapateco/anaap

☐ Español/amaaxün

☐ Otro/biijnk

____
(¿Cual?/juu')

10a. ¿Qual idioma prefiere hablar?/juu' tse'e nüyojk mkëjtsp

☐ Mixe/ayöök

☐ Zapateco/anaap

☐ Español/amaaxün

☐ Otro/biijnk

____
(¿Cual?/juu')

11. Pertenece a algun grupo etnico/pën jayus mitse'e:

☐ Mixe/ayöök ☐ Zapateco/anaap

☐ Chinanteco/akats ☐ Mestizo/agats

☐ Otro/biijnk

____
(¿Cual?/juu')

12. ¿Depende alguien de usted económicamente?/jäme'e pëne'e mmëkkijup m'ajootijup

☐ Sí/be'em ☐ No/ka'a

12a. Si contesta "Sí", ¿cuantas personas depende de usted?/pëm be'em nübinxüp tse'e mmëkkajada m'ajootajada ______

12b. ¿Depende usted de alguien económicamente?/jä tse'e pën mitse'e mmëkkip m'ajootip

☐ Sí/be'em ☐ No/ka'a

DISCAPACIDAD

13. Tipo de lesión/ti se'e mjajtjup (Señale los que se relacione con su discapacidad):

- ☐ Amputación
- ☐ Artritico
- ☐ Autismo
- ☐ Ciego
- ☐ Cuadraplejia
- ☐ Debil Visual
- ☐ Distrofia Muscular
- ☐ Epilepsia
- ☐ Hemiplejia
- ☐ Mielomeningocele
- ☐ Paralisis Cerebral
- ☐ Paralisis Infantil
- ☐ Paraplejia
- ☐ Polio
- ☐ Problemas de Desarollo
- ☐ Síndrome de Down
- ☐ Sordo/Mudo
- ☐ Malformaciones Congenitas
- ☐ Otro ______________________
  (¿Cual?/biijnk)

14. Tiempo de lesión: ____________ años/ binxüp jekani mitse'e mtsaacha.

15. Origen de la discapacidad/tyëjxs mitse'e mkanatyö'k tsotsa:

- ☐ Secuela de enfermedad/ps'smhëjx mitse'e
- ☐ Accidente/jifü'üm mdaajny
- ☐ Congenito/mmukä'xi

Instrucciones: Señale los que se relacione con su discapacidad.

16. ¿Qué parte del cuerpo afecta la discapacidad?/dömakejxs mitse'e mganatyö'k tsotsa

- ☐ Audición/mgamotup
- ☐ Cerebral/mgubajkyp
- ☐ Habla/mjojtsün
- ☐ Miembro Inferior Derecho/ m'aka'yündek
- ☐ Miembro Inferior Izquierdo/ m'anajütek
- ☐ Miembros Inferiores/ banmäjtsk mdë'ëk
- ☐ Miembros Superiores/ banmäjtsk mgë'ëj
- ☐ Miembros Superiores e Inferiores/ mgë'ëjumdek
- ☐ Miembro Superior Derecho/ m'aka'yün gë'ëj
- ☐ Miembro Superior Izquierdo/ m'anaju kë'ëj
- ☐ Visual/m'ixün
- ☐ Otro/biijnk ____________________

17. ¿En el área donde vive existen recursos o instituciones para el apoyo de su discapacidad?/ya jöma mdsüüna jä tse'e pëëmdük ukpü jayu ju'u mbutëjkijidup ax jö'n mganatyö'k tsotsa

☐ Sí/be'em ☐ No/ka'a

17a. ¿En caso de ser afirmativo cuales son?/pën be'em juu's jä'ä be'eda

- ☐ Acceso Libre
- ☐ CREE
- ☐ IMSS
- ☐ Instituciones Privadas
- ☐ ISSSTE
- ☐ SSA
- ☐ Otro/biijnk

____
(¿Cual?/juu')

17. A su consideración que tipo de apoyo necesita/juu' tse'e mbingopkja'bipjats myaktukputëkat:

- ☐ Apoyo familiar/mjënjëtmdëkjëët
- ☐ Apoyo psicológico/mbinma'yëngëjx
- ☐ Atención medica/tsoojy
- ☐ Capacitación/töönk nü'ixpëjkin
- ☐ Educación/ixpëjkün
- ☐ Otro/biijnk ______________________
  (¿Cual?/juu)
- ☐ Empleo/töönk
- ☐ Información/juu' myaktukbinjabat
- ☐ Rehabilitación fisica/ mni'kxümyupk yakmëkkinmo'ot
- ☐ Salud/mëkkin tsotsin

18. ¿A su consideración cuales son las necesidades más urgentes para los discapacitados?/tis mitse'e m̃nasja'bip jatsele bingopk tundsojk yaktukputëkadat ja jayu juu' kanatyö'ktsotsadap ¿Por qué?/tyëjx

____

____

____

____

Interview Questions for Person with a Disability

1) Please explain the meaning of disability from the Mixe point of view.

    1a) Please describe your disability.

2) What services are available to people with disabilities in Totontepec?

    2a) If there are services, are they sufficient? Please explain.

3) Please discuss how your disability has affected your life.

4) Do you have work in the community?

    4a) How does your disability affect your ability to work?

5) What is your greatest need?

6) What is your greatest concern or fear for the future?

7) Who do you believe has the responsibility to assist people with disabilities?

8) What do you believe should be done so that work with people with disabilities can continue?

Interview Questions for Family Members

1) Please explain the meaning of disability from the Mixe point of view.

    1a) Please discuss your family member's disability.

    1b) What affect has your family member's disability had on your family?

2) Please describe the type of care or assistance you provide to your family member with a disability.

3) What is your greatest need?

4) What do you perceive as being your relative's [with a disability] greatest need?

5) What is your greatest concern or fear for the future?

6) Who do you believe has the responsibility to assist people with disabilities?

7) What do you believe should be done so that work with people with disabilities can continue?

Appendix E

Letter of Authorization

H. Ayuntamiento Constitucional
Totontepec Villa de Morelos,
Mixe, Oax.

Dependencia: PRESIDENCIA MUNICIPAL
TOTONTEPEC VILLA DE MORELOS,
Sección: ADMINISTRATIVA.
Número: S-N
Expediente: AUTORIZACIONES ' 97

ASUNTO: SE CONCEDE AUTORIZACION.

Totontepec Villa de Morelos, Mixe, Oax., a 1o. de Marzo de 1997.

C. ADRIAN ROJAS MARTINEZ
PRESENTE.

El que suscribe ciudadano Octavio Molina Maldonado Presidente Municipal Constitucional de esta población, AUTORIZA a usted hacer visitas domiciliarias a personas discapacitadas en la comunidad.

En espera de que desempeñe esta labor, le reitero mis agradecimientos.

ATENTAMENTE.
SUFRAGIO EFECTIVO. NO REELECCION.
"EL RESPETO AL DERECHO AJENO ES LA PAZ".
EL PRESIDENTE MUNICIPAL

C. OCTAVIO MOLINA MALDONADO

Appendix F

Community Meeting Agenda

Totontepec Villa de Morelos Mixe Oaxaca, Mexico

PRESENTACION DE LA INVESTIGACION ACERCA DE LOS DISCAPACITADOS DE LA COMUNIDAD DE TOTONTEPEC MIXE OAXACA

DURANTE LOS DIAS 28 Y 29 DE SEPTIEMBRE DE 1997.

* *

EN EL ALBERGUE ESCOLAR
"JULIO DE LA FUENTE"

28 DE SEPTIEMBRE DE 1997

9:00 **DESAYUNO**
En el Albergue Escolar "Julio de la Fuente"

10:00 **INAUGURACION**
C. OCTAVIO MOLINA MALDONADO
Presidente Municipal Constitucional de
Totontepec Villa de Morelos Mixe, Oax.

11:00 **OBJETIVO Y PROCESO DE LA INVESTIGACION**
C. RAQUEL RIVERA GOMEZ
Enfermera de la Clínica IMSS SOLIDARIDAD 004 de Totontepec
Villa de Morelos.
ING. JUAN ARELI BERNAL ALCANTARA
Promotor de Desarrollo Comunitario de SEDAF* y Director del
Instituto Comunitario Mixe Kong Oy de Totontepec Mixe Oax.

10:30 **RESULTADOS:**
CUANTITATIVOS
IV, M. A. GEORGE GOTTO
UNIVERRSIDA DEL NORTE DE ARIZONA
CUALITATIVOS
DRA. CRC CATHERINE MARSHALL
UNIVERSIDAD DEL NORTE DE ARIZONA
* DISCUSIÓN
12:30 **DESCANSO**

13:00 **INDIGENAS CON DISCAPACIDAD EN ESTADOS UNIDOS DE NORTEAMERICA**
M. C. ELA YAZZIE KING
REPRESENTANTE DE LA NACIÓN NAVAJO

14:30 **COMIDA**
En el Albergue Escolar "Julio de La Fuente"

*SEDAF Secretaría de Desarrollo Agropecuario y Forestal

16:00 REHABILITACION INTEGRAL
C. PEDRO FLORES REY
Miembro de Acceso Libre A. C. Oaxaca, Oax.

C. OVALDO GALICIA
Presidente de la Asociación de Discapacitados de la Mixteca,
Huajuapan de León, Oax.

17.00 EXPERIENCIA DEL CENTRO DE REHABILITACION DE PIÑA PALMERA
DRA. ANNA JOHANSSON DE CANO
Directora del Centro de Rehabilitación de Piña Palmera en Zipolite,
Puerto Angel, Oax.

18:00 ENCUENTROS DEPORTIVOS:
* Basket ball de dos equipos de deportistas en sillas de ruedas del DIF
* Boleibol entre un equipo mixto de la comunidad contra un equipo de deportistas con problemas de audición del DIF.

20:00 MUSICA CON LA BANDA FILRMONICA DE TOTONTEPEC.

21:00 CENA
En el Albergue escolar "Julio de la Fuente"

29 DE SEPTIEMBRE DE 1997

9:00 **DESAYUNO**
En el Albergue Escolar "Julio de la Fuente"

10:00 **SERVICIOS DEL DIF PARA LOS DISCAPACITADOS**
DR. GERMAN VARGAS GUZMAN.
Director de Salud Reproductiva y Atención a Discapacitados

11:00 **REHABILITACION FISICA**
Fisioterapeuta del DIF.

12:00 **CONCLUSIONES Y PLANES PARA EL FUTURO:**

PARTICIPACION DE TODOS LOS PARTICIPANTES

Mesas Redondas y Plenario

13:00 **INAUGURACION DEL CENTRO MIXTO DE REHABILITACION**
DR. GERMAN VARGAS GUZMAN

EN LA CLINICA IMSS SOLIDARIDAD

14:00 **COMIDA Y DESPEDIDA**
En el Albergue Escolar "Julio de la Fuente"